



MedStar Georgetown University Hospital

Cochlear Implant Program

Patient Information Packet

Table of Contents

Clinic and Contact Information

- Welcome to MGUH Page 3
- Cochlear Implant Team & Clinic Info Page 4

Getting Started

- What is a Cochlear Implant? Page 5
- Candidacy Evaluation Pages 6-8
- Meningitis Vaccination Recommendation Pages 9-10

Surgery Information

- Surgery Day Page 11
- Risks with Surgery Page 12
- After Surgery Page 13

Moving Forward

- Audiology Appointments Page 14
- Initial Activation Page 15
- Recommended Follow-up Pages 16 – 18
 - One Week Post Activation
 - One Month Post Activation
 - Three Months
 - Six Months
 - One Year
- Aural Rehabilitation Pages 19 – 20
- Support and Resources Pages 21-22

Welcome to MGUH

Welcome to the Georgetown University Hospital Cochlear Implant Program!

Congratulations on taking the first step towards determining if a cochlear implant (CI) may be right for you! The aim of this packet is to provide you with important information as you begin the process towards cochlear implantation and continue to provide you with details if you decide to move forward with a cochlear implant. The decision to proceed with a cochlear implant can be difficult, 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. We work with all three FDA approved cochlear implant companies: Advanced Bionics, Cochlear Corporation, and MED-EL.

Many individuals wonder how much improvement they would receive by having a cochlear implant. Results can range from sound detection to understanding speech in difficult situations. Benefit can depend on several things including hearing history, history of hearing aid use, and access to spoken language. Success with a cochlear implant depends on wearing the device full-time, practice, and returning for follow-up visits. A patient's motivation and realistic expectations are important factors in a patient's cochlear implant candidacy.

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

Adult Cochlear Implant Team & Clinic Information

SURGEONS

H. Jeffrey Kim, MD, FACS
*Professor, Otolaryngology/Neurotology
Otolaryngology – Head and Neck Surgery*

Michael Hoa, MD
*Assistant Professor, Neurotology/Otology
Otolaryngology – Head and Neck Surgery*

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

Mary Finkbone, Au.D., CCC-A
*Clinical Audiologist
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Laura Levin, Au.D., CCC-A
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MGUH DEPARTMENT OF OTOLARYNGOLOGY AND HEAD & NECK SURGERY

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What is a Cochlear Implant?

As you may already realize, a cochlear implant is vastly different than a traditional hearing aid. Simply put, a traditional hearing aid picks up sound via a microphone, and amplifies it before sending the signal through your auditory system. This is an **ACOUSTIC** signal. With significant damage, a hearing aid may not be sufficient in providing audibility and clarity.

A cochlear implant uses an **ELECTRICAL** signal to stimulate your acoustic nerve and transport the information to your brain via a surgically placed internal component. The sound is picked up by the microphones of an external piece worn behind the ear or on the head and communicates with the internal implant. This external processor can be taken off throughout the day. The image below illustrates how the processor and implant work together.

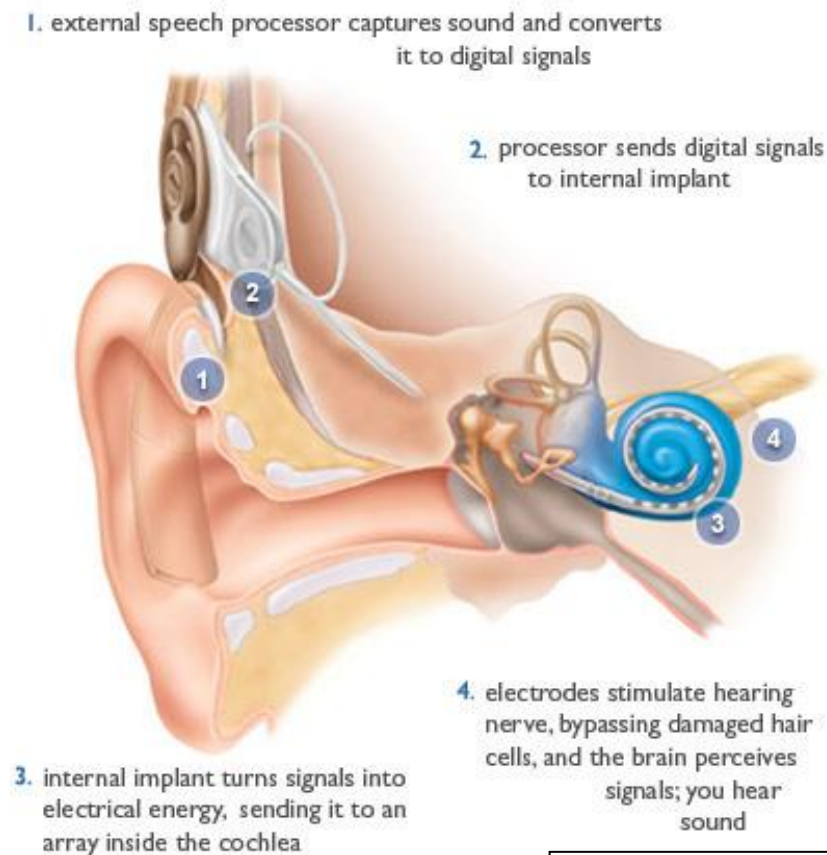


Image from Cochlear Corporation

Evaluation Process

WHAT IS THE GOAL OF A COCHLEAR IMPLANT EVALUATION?

- Determine if you are a cochlear implant candidate
- Provide information on how cochlear implants work
- Decide if cochlear implantation is right for you
- Choose preferred cochlear implant manufacturer

EVALUATION PROCESS

- Audiologic Evaluation
 - Standard hearing test (if needed)
 - Test speech understanding with and without hearing aids
 - Discuss candidacy, expectations with a CI, timeline of appointments
- Medical Evaluation
 - A doctor who specializes in ears and cochlear implants will review your medical history
 - You will likely be referred for a CT scan and/or MRI
 - The doctor will review the surgery, risks, and follow-up care

IMPORTANT CANDIDACY INFORMATION

- Cochlear implant candidacy is made up of several factors, including your medical status, audiologic results, and benefit from hearing aids. The following criteria are also important in determining if you are a good cochlear implant candidate:
 - Realistic expectations
 - Understanding of the effects of cochlear implantation
 - Commitment to wear the processor and follow the recommended appointment timeline

Evaluation Process

EXPECTATIONS WITH A COCHLEAR IMPLANT

Patient expectations can be a sensitive and critical issue to address both pre-operatively and post-operatively with not only the patient undergoing the surgery, but with the patient's family and friends. Post-operative outcomes for cochlear implant recipients can take many recognizable forms, including sound detection at the most basic level to open-set speech recognition (referring to the patient's ability to identify what is said without prior knowledge of what the word or sentence choices are) in noise.

The amount of benefit that a patient perceives is largely dependent on his/her past hearing history and exposure to amplification and spoken language. Patients who developed spoken language prior to the onset of significant hearing loss are routinely identified as post-lingually deaf. A patient with this hearing background is different from a patient whose primary means of communication is through sign language or other forms of manual and visual communication. Patient's who rely on sign language are often described as being pre-lingually deaf, meaning that the hearing loss preceded his/her development of spoken language. Post-lingually deafened adult patients tend to have better outcomes than pre-lingually deafened adult patients after cochlear implantation.

Research has shown auditory verbal therapy and speech-language rehabilitation to be viable means for improving speech perception outcomes for most cochlear implant recipients. Referral for these services is optional for each patient and can be discussed with your audiologist and speech-language pathologist. We are supportive of this decision. Both post-lingual and pre-lingual patients can be excellent candidates for cochlear implantation. We review each patient as a unique and separate case. Cochlear implantation is a life-changing experience and we believe in serving all of our patients to the best of our knowledge and expertise.

Evaluation Process

COCHLEAR IMPLANT DISCUSSION

Manufacturer: _____

Processor Model(s): _____

Implant Model: _____

Processor Color: _____

Other:

For more information regarding your chosen manufacturer, or to speak with a representative of your cochlear implant manufacturer please visit the corresponding websites:

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 Recommendation

Meningitis is a possible, albeit very rare, complication of cochlear implantation. However, when present it can cause serious consequences.

Meningitis is an infection of the lining of the surface of the brain. Early symptoms of meningitis include fever, irritability, lethargy and loss of appetite in infants and young children. Older children and adults may also manifest headaches, stiff neck, nausea, vomiting, and confusion or alteration in consciousness. Physicians are encouraged to consider a diagnosis of meningitis in cochlear implant patients when such symptoms exist and to begin appropriate treatment as soon as possible.

The occurrence of meningitis can be decreased even further through the use of appropriate vaccination. On the next page, you will see recommendations from the United States Centers for Disease Control and Prevention (CDC). Please take this information to your primary care physician.

We recommend vaccinations for patients with cochlear implants. If you have any questions regarding this issue, please contact your physician.

Meningitis Vaccination Recommendation

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 (<http://www.cdc.gov/vaccines/vpd-vac/mening/cochlear/dis-cochlear-gen.htm>).

- 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.

Meningitis Vaccinations Acknowledgement Letter

I acknowledge that I have received information from my physicians regarding the recommended vaccinations against bacterial meningitis.

Patient Name Printed

Patient Signature

Date

Surgery Day

- The procedure is performed in a day surgery unit with most patients going home the same day.
- General anesthesia is administered in the operating room, and a small amount of hair behind the ear is shaved, if necessary.
- An incision is made in the crease behind the ear, which makes the scar very inconspicuous once it has healed.
- A pocket is created under the skin to accommodate the internal receiver-stimulator portion of the implant. This part of the implant has a very flat design so that it will not produce a noticeable shape.
- An opening is then made into the air-filled bone called the mastoid. This mastoidectomy allows us to access the cochlea without disturbing the ear canal or eardrum.
- A very small opening is made into the cochlea, and the implant electrode is threaded in as far as possible.
 - Most cochlear anatomies can accommodate the complete electrode unless a cochlear abnormality is present, in which case a partial insertion may be necessary.
- 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.
- Pain is mild-to-moderate for 1 to 2 days and can be controlled with oral pain medicines.
- Some patients experience imbalance for a few days after surgery, but this resolves within the first week.

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 thrusting out (extrusion) of 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 being put to sleep or general anesthesia (problems with the heart, lungs, kidneys, liver and brain due to general anesthesia)

After Surgery

- You will return one-week post-surgery for a follow-up with your doctor.
- Most patients are able to return to school/work at this point.
- 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.
- After that, there are no activity restrictions.
- The initial activation of the device and placement of the external equipment is performed 4 weeks after surgery at your audiologist's office.
 - This time allows your incision site to heal and for swelling to diminish.

Audiology Appointments

Your initial activation will take place approximately 4 weeks post-surgery. This time is required to allow your incision site to heal. At your activation the cochlear implant will be programmed and turned on for the first time! This appointment can be very exciting and overwhelming at the same time. Our main goal on this day is SOUND DETECTION, and to begin providing your auditory nerve and brain with new stimulation.

It is important to remember that at first, the sound from the cochlear implant may sound strange and unclear. Many patients even describe the sound as 'robotic' or 'cartoonish'. Everyone who receives a cochlear implant adapts to the stimulation at a different rate, but most changes can occur up to a year following activation. The quality of the sound will improve over time and with practice.

More detailed instructions regarding activation day will be available during your appointment. Your brain adapts to the cochlear implant most quickly within the first weeks to months, which is why additional appointments are recommended in the beginning. Below is a timeline of the recommended audiology follow-ups. The next few pages outline the recommended audiology appointment timeline once your cochlear implant has been activated. It shows a broad example of what you may do at follow-up appointments.

AUDIOLOGY TIMELINE

- Activation (~4 weeks post-surgery)
- 1 Week Post-Activation
- 1 Month Post-Activation
- 3 Months Post-Activation
- 6 Months Post-Activation
- 1 Year Post-Activation
- Annual Follow-up

Initial Activation

- We will ask you to leave out your hearing aid for the appointment. Afterwards, you will most likely be able to wear your cochlear implant and hearing aid together.
- You will be fit with your external equipment (processor, cables, magnets, etc.)
- Testing of the internal implant
- A program or 'map' will be created based off of your responses to very soft sounds as well as louder sounds.
 - At follow-up appointments, your processor will be re-programmed or "re-mapped" to see if changes should be made.
- The microphones will be turned on to 'activate' your cochlear implant. We will talk to you about what your hearing or perceiving, and use your feedback to make adjustments as needed.
- Once programming has been finished for the day, the settings will be saved to your processor as well as our computer.
- We will discuss how to use, troubleshoot, and maintain the equipment. This can include the processor, remote control, and accessories (if applicable).
 - If there is not time to review everything that is OK. You will return in one week for your first follow-up
- Recommendations following your activation:
 - Wear the cochlear implant as much as possible (all waking hours would be our recommendation)
 - Review the user manuals

ACTIVATION DAY PROGRAMMING

1. _____
2. _____
3. _____
4. _____

Audiology Follow Up

ONE WEEK POST ACTIVATION

- Re-mapping
- Hearing test without the cochlear implant
- Discussing additional parts or accessories not discussed at activation
- Today's programming
 - Program 1:
 - Program 2:
 - Program 3:
 - Program 4:

Notes:

ONE MONTH POST ACTIVATION

- Re-mapping
- Testing with the cochlear implant
- Speech testing with the cochlear implant
- Listening exercises
- Today's programming
 - Program 1:
 - Program 2:
 - Program 3:
 - Program 4:

Notes:

Audiology Follow Up

THREE MONTHS POST ACTIVATION

- Re-mapping
- Listening exercises
- Testing with the cochlear implant
- Speech testing with the cochlear implant
- Today's programming
 - Program 1:
 - Program 2:
 - Program 3:
 - Program 4:

Notes:

SIX MONTHS POST ACTIVATION

- Re-mapping
- Testing with the cochlear implant
- Speech testing with the cochlear implant
- Today's programming
 - Program 1:
 - Program 2:
 - Program 3:
 - Program 4:

Notes:

Audiology Follow Up

ONE YEAR POST ACTIVATION

- Re-mapping
- Testing with the cochlear implant
- Speech testing with the cochlear implant
- Today's programming
 - Program 1:
 - Program 2:
 - Program 3:
 - Program 4:

Notes:

TWO YEARS POST ACTIVATION

- Re-mapping
- Testing with the cochlear implant
- Speech testing with the cochlear implant
- Today's programming
 - Program 1:
 - Program 2:
 - Program 3:
 - Program 4:

Notes:

Aural Rehabilitation

Your cochlear implant has been activated and you are beginning to listen to a world that you haven't heard in a long time. You and your audiologist have programmed the settings to give you adequate sound input. **What happens next?**

It has been mentioned previously that active listening and practice with the cochlear implant are positive factors in increasing speech understanding. Research has shown that listening practice or exercises, known as Aural Rehabilitation or Aural Rehab, can increase the rate of progress a patient experiences.

Aural Rehab is made up of exercises and programs designed to teach you how to listen through your cochlear implant. This can be done with the help of a professional, like a speech-language pathologist, or at home on your own. Informal at home training can be as easy as listening to audio books through your cochlear implant. Listed below are several programs and websites designed to assist you in your aural rehabilitation. Many of these sites have designed self-guided listening exercises that allow you to move through programs at your own pace.

FREE ONLINE RESOURCES

- **Communication Corner:** <http://www.cochlear.com/wps/wcm/connect/us/communication-corner>
- **Advanced Bionics Sound Success** <http://www.absoundsuccess.com/>
- **The Listening Room:** <http://thelisteningroom.com/>
- **SoundScape:** <http://www.medel.com/us/resources-for-success-soundscape/>
- **Angel Sound:** http://angelsound.tigerspeech.com/angelsound_about.html
- **TED Talks:** <https://www.ted.com/talks> (watch with closed captioning)

ADDITIONAL ONLINE RESOURCES (APPS/LISTENING PROGRAMS)

- **A-B Apps:** <https://advancedbionics.com/us/en/home/support/ab-apps.html>
 - iPhone or Android
 - rehab Catalogue App
 - able CLIX
 - myNaida CI
- **Cochlear App:** <http://www.cochlear.com/wps/wcm/connect/us/recipients/nucleus-5/nucleus-5-support-and-community/self-support/nucleus-5-app>
 - iPhone or Android
 - Nucleus Support App
 - HOPE Words App
- **MED-EL Apps:** <http://www.medel.com/us/us-listening-apps/>
 - iPhone or Android
 - Oceans & Continents
- **i-Angel Sound:** <https://itunes.apple.com/us/app/i-angel-sound/id839199212?mt=8>
 - iPad only
- **Speech Banana:** <https://itunes.apple.com/us/app/speech-banana/id944371734?mt=8>
 - iPad only
- **LACE (Listening and Communication Enhancement)** <https://www.lacelistening.com/>
- **iHearThat App**
 - Ling 6 Sound Practice
- **Hear Coach App** by Starkey
- **Speech ID App**

LOW TECH OPTIONS

- Listening to TV/Netflix/Hulu with closed captioning
- Reading book or newspaper aloud
- Engaging in listening practice with friends or family members

LANGUAGE RESOURCES

- **Spanish Resources:** <http://hope.cochlearamericas.com/reading-room/spanish>
- **Multiple language resources:** <http://www.bbc.co.uk/languages/>

EXTRA HELP

- **Audio Books:** <https://www.overdrive.com/#>
 - Allows you to connect to your library's online collection using a tablet or phone
 - Does require you to have a library card
- **Additional listening exercises:** <http://www.manythings.org/>
 - Designed for English as Second Language (ESL) individuals, this site offers many different listening exercises as well as games that can be beneficial to CI users
- **Finding movie theatres with closed captioning:** <http://www.captionfish.com/>
- **Clear Captions App**
 - For closed captioning when placing or receiving a call on your smart phone
 - iTunes or Android (Free)
- **Live Caption App**
 - For closed captioning when listening to speech in person
 - iTunes or Android
 - <http://www.livecaptionapp.com/>

Support and Resources

PATIENT SUPPORT

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

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

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

In addition to patient support offered through the manufacturer, there are several helpful websites and online communities for individuals who have received or are considering a cochlear implant. These sites can be found easily through internet search engines.

MANUFACTURER TECHNICAL SUPPORT

Advanced Bionics

- Customer service: www.advancedbionics.com/us/en/support
 - Phone: 1-877-829-0026
 - Email: CustomerService@AdvancedBionics.com
- Advanced Bionics Store: shop.bionicear.com
 - Purchase of items or parts can be made directly through the AB store
- myAB Online
 - <https://advancedbionics.com/us/en/portals/consumer-portal.html>

Cochlear Corporation

- 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
 - Purchase of items or parts can be made directly through the store
- Reimbursement & Insurance
 - Phone: 1-800-633-4667 (option 2)

MED-EL

- 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>
 - Purchase of items or parts can be made directly through the WebShop