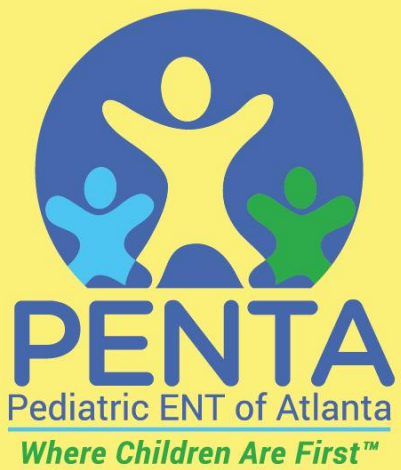




PARENT & PATIENT HANDBOOK



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Commonly Asked Questions

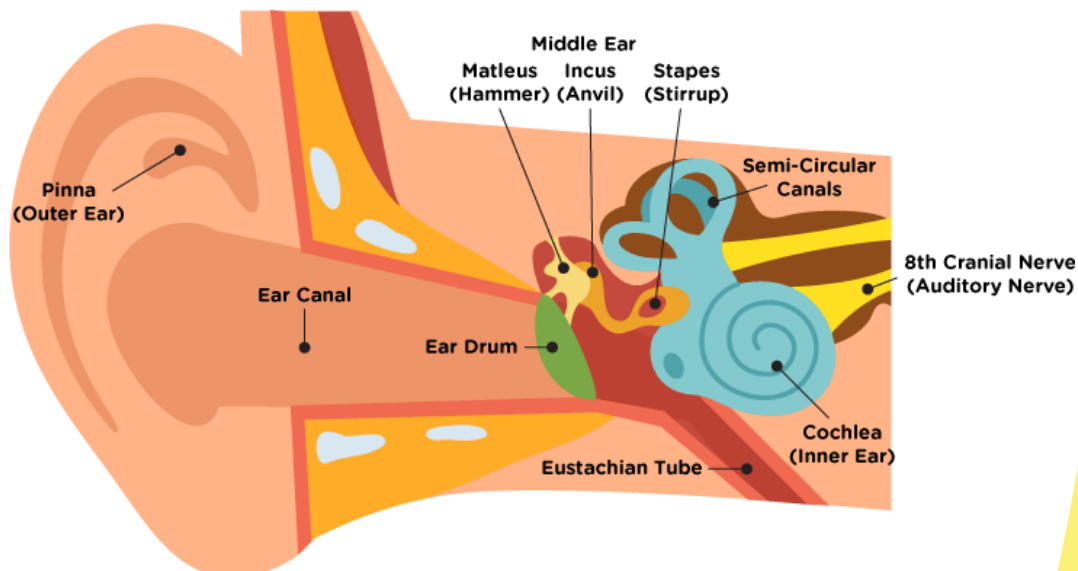
How does the ear work?

The ear is made up 3 parts: an outer ear, middle ear, and inner ear. The part we can see is the outer ear and includes the ear canal. It captures sound energy and funnels it to the ear drum. The middle ear is an air pocket behind the ear drum and contains three hearing bones.

Sound waves hitting the ear drum create vibrations that are transmitted down the hearing bones to the inner ear (cochlea). The cochlea is a fluid filled structure with sensory cells called hair cells. The hair cells translate the vibrations into patterns of stimulation for the auditory nerve.

The auditory nerve then takes this information to the brain. In this way, the inner ear changes the sound vibrations into signals the brain understands.

In children with severe or profound hearing loss, the hair cells and/or part of the auditory nerve are damaged, preventing the sound signals from being transmitted to the brain. This is called sensorineural hearing loss.



What is a Cochlear Implant?

A cochlear implant is an electrode that is placed in the inner ear (cochlea) to bypass the damaged hair cells. It is made of two parts: the external processor and the internal implant. The external processor is also called the speech processor or sound processor.

Sounds in the environment are picked up by the microphone and filtered by the speech processor into coded signals. The coded signals are then sent to the transmitting coil, which transmits the signals through the skin to the implanted receiver.

The receiver electrically activates the electrode array, which in turn stimulates the auditory nerve. Nerve impulses are sent to the brain where they are interpreted as sound.

The cochlear implant was invented around 30 years ago to help severe to profoundly deaf persons communicate more easily. Thanks to extensive research and evolving technology of the device, the device has become a valuable option for persons with significant hearing loss.

Cochlear implants are recognized by the American Medical Association (AMA) and the American Academy of Otolaryngology Head and Neck Surgery (AAO-HNS) as an approved medical procedure for children. They were approved by the Food and Drug Administration (FDA) in the mid-1980's and are covered by insurance policies, Medicare, and Vocational Rehabilitation. There are now more than 60,000 individuals worldwide who have received cochlear implants.



After my child receives a cochlear implant, will they be able to hear and talk like normally hearing children?

Once your child receives a cochlear implant, they will be able to hear sounds that they were previously unable to hear with hearing aids. Although your child will hear more sounds, your child will need to be trained to use and understand these sounds.

Receiving a cochlear implant is simply the first step in a long process. Your child will only learn the meaning of sounds and words through intensive rehabilitation. The degree of success your child will have in developing listening and speech skills cannot be predicted, however, with proper auditory training and listening therapy, your child will have the best chance of being a successful implant user.

Remember when your child is not wearing their sound processor, they have a profound hearing loss.

How do I know if my child is a cochlear implant candidate?

Before receiving an implant, each child is carefully evaluated by the PENTA Cochlear Implant Team to determine if an implant is right for them. Children between the ages of 12 months and 18 months who have profound hearing loss in both ears and who receive little benefit from hearing aids are candidates.

Children 18 months to 17 years who have severe to profound hearing loss in both ears and receive little to no benefit from hearing aids are also candidates. Although these are general guidelines, each child receives a thorough and individualized evaluation to determine candidacy.



How does the evaluation work?

PENTA Cochlear Implant Evaluation Process

1. Please contact the PENTA Cochlear Implant team at 404-591-1884 to receive our information packet.
2. Once you have received our packet, please complete and return all requested paperwork.
3. When all paperwork has been reviewed, the team audiologist will schedule an initial consultation. This visit will comprise of a thorough introduction to the currently available implant systems and a counseling session with respect to the cochlear implant procedures at PENTA.
4. An appointment for audiological testing will be scheduled.
5. Your audiologist will set you up with a consumer specialist from each manufacturer for you to ask further questions.

If your child appears to be a cochlear implant candidate

1. A computed Tomography (CT scan) and/or Magnetic Resonance Imaging (MRI) evaluation(s) will be scheduled and reviewed to determine the structure of the inner ears.
2. A consultation with your child's ENT physician will be scheduled after initial audiological studies have been completed. At this appointment, your child's overall health will be evaluated. A detailed ear evaluation will also take place.
3. Additional testing such as psychological, cognitive, and speech-language testing may be scheduled, as determined by the PENTA cochlear implant team.
4. Once a specific device has been chosen, further audiological testing may need to be completed.

Surgical Questions

What does the surgery involve?

Cochlear implant surgery usually takes from 3-5 hours. During the operation, the internal device is placed under the skin and the electrode array is implanted into the inner ear (cochlea).

Implant patients stay overnight at Scottish-Rite Children's Hospital and are cared for by experienced nurses and staff. The hospital allows one family member to stay overnight in the room with your child. Additional family members are welcome to stay in the lounge area(s) as well.

How safe is surgery?

Cochlear implants are recognized by the American Medical Association (AMA) and the American Academy of Otolaryngology Head and Neck Surgery (AAO-HNS) as an approved medical procedure for children. They are approved by the Food and Drug Administration (FDA).

In general, the surgical procedure is not considered dangerous or particularly painful. As with any surgical procedure, patients should be aware that there are risks associated with anesthesia. A very small percentage of patients may experience some postoperative effects such as inflammation or bleeding at the surgical site, numbness or stiffness around the ear, injury or stimulation of the facial nerve, taste disturbance, dizziness, ringing in ears (tinnitus), neck pain, or fluid leak from the cochlea, which could result in meningitis.

When will I find out what time surgery will be and if my child will be able to eat prior to surgery?

The Scottish-Rite Children's Hospital Same Day Surgery Department will call you the day before your child's surgery with arrival times, feeding instructions, and surgery procedures.

How do I prepare my child for surgery?

The PENTA team wants you and your child to feel as relaxed as possible on the day of your child's operation. If any questions or

concerns arise between your visit with the physician and the day of surgery, please contact us at (404) 255-2033.

What is the step-by-step process for the day of surgery?

1. The day of surgery you will report and register on the first floor of Scottish-Rite Children's Hospital.
2. After registering, you will be taken to a room where your child will change into hospital clothes, have vital signs taken, and be evaluated by an anesthesiologist.
3. After the final examination, the child may be given an oral sedative. The patient will then be transported to the operating room for the procedure.
4. It will be approximately 3-5 hours for all events to take place, which include the pre-operative time, patient surgery time, and patient recovery time. The surgery may be longer if your child is receiving two cochlear implants on the same day.
5. During the time they are in surgery, you may go to the cafeteria or wait in the Day surgery waiting room.
6. After surgery your child will be taken to the recovery room where he/she will remain for approximately one hour.
7. The recovery room nurses will notify you when your child is ready to be transported so you can accompany him/her to the floor where he/she will be observed overnight.

What happens the day after surgery?

The following day, your child will have the dressing removed and the surgical site inspected. The bandage will then be replaced around your child's head.

If all is well, discharge instructions will be reviewed, and you and your child will be discharged from the hospital after breakfast.

Will I be notified of my child's progress during surgery?

You may request that a nurse give you periodic updates during surgery so that you will know how the surgery is proceeding. After surgery, the physician will speak with you to inform you of all aspects of the surgery and whether all the electrodes were inserted.

How will my child look after surgery?

The internal part of the implant is not visible after surgery. Your child's hair will have been shaved in the area where the incision was made during surgery. The bandage that is placed over the incision at the end of surgery will remain on the head overnight and is changed the next day.

This bandage will remain on your child's head for several days. After the incision behind the ear heals, a slight bump may remain. This is covered by your child's hair. Depending on the hair's length, more or less of the external portion of the device will be visible.

How long is the recovery period?

Typically, kids bounce back from cochlear implant surgery very quickly. Usually, it involves an overnight stay in the hospital and an additional week at home to let the incision site heal. Children usually return to school after one week, however, physical activity should be limited for three weeks.

What kind of follow up occurs after surgery?

One week after surgery, your child will see the physician, who will inspect the incision site. At this appointment, the physician will check your child's incision area and remove any steri-strips from the incision site. Please allow one hour for this appointment.

Approximately 2 weeks after your child's surgery, you will receive the cochlear implant sound processor and accessories. It is during this appointment, called the "Initial Stimulation", that your child will hear with the implant for the first time.

What should I expect at the Initial Stimulation?

Each implant must be specifically programmed, or "mapped", for each individual patient. Our audiologist is the person who programs the device. Programming the sound processor involves working with your child to develop unique sets of intensity levels for each frequency (pitch).

In other words, we determine the power levels required by the cochlear implant to stimulate the nerve and be perceived (or "heard") by your child at certain frequencies (pitches).

Every child reacts differently to the initial stimulation. Some children cry, others laugh, and some do not give any indication that they are hearing. There is no way to predict how your child will respond that first day, however, after a few weeks of use, most children tolerate their implant and begin to respond to sounds. Initial stimulation may be completed over a 1-2-day period.

How often does my child need to be mapped?

During the first few months, your child will be seen by an audiologist often. Typically, children are seen at their initial stimulation, one week after stimulation, two weeks later, and then one month later. If your child is adjusting well, appointments may be scheduled once every three months. Eventually, most children are seen for mapping about two times a year.

Does the PENTA Cochlear Implant Team communicate with my child's teachers and other educational professionals?

The PENTA audiologists work closely with each child's school both during the evaluation process and after implantation. All available audiological records are reviewed and incorporated as possible. The audiologist and the school communicate regularly and work together to help your child succeed with their cochlear implant.

Will insurance pay for it?

Cochlear implantation is covered by most insurance policies as well as Medicaid. Our insurance specialists will work to secure written confirmation that your plan covers the device and procedures prior to the surgery. You may be responsible for a portion of the costs. Depending on your benefits, you may need to meet a deductible.

Where do patients come from?

Many of our patients come from the greater Atlanta area. We see many children from the state of Georgia and surrounding states, such as South Carolina, Tennessee, and Alabama.

Why do patients choose PENTA?

We are committed to the success of every hearing-impaired child and truly care about the well-being of our patients and their families. To find out more about each device, please visit the companies' web sites.

Cochlear: www.cochlear.com
Advanced Bionics: www.cochlearimplant.com
Med-El: www.medel.com

Additional resources:

American Academy of Audiology
www.audiology.org

Atlanta Speech School
<https://www.atlantaspeechschool.org/>

Auditory Verbal Therapy
<https://www.avchears.org/>

Auditory Verbal International
www.auditory-verbal.org

Georgia Early Intervention (Babies Can't Wait)
<https://dph.georgia.gov/babies-cant-wait>

Georgia Center for Deaf and Hard of Hearing
<https://www.gcdhh.org/>

Glossary of Terms

American Sign Language (ASL): A language which is communicated by signs, expressions, and gestures, rather than by spoken speech. ASL is a unique language with its own grammar and syntax, differing significantly from written or spoken English.

Assistive Listening Devices (ALD's): Products designed to aid hearing impaired persons. They help clarify speech and reduce the effects of background noise in everyday situations, such as watching TV, movies, theaters, places of worship, or alert a person to a doorbell chime, telephone ring, or alarm clock sound.

Auditory Nerve Fibers: The part of the auditory system that carries signals from the ear to the brain for interpretation. This nerve takes input from the ear to the brain.

Auditory-Oral Education: The focus on this educational approach is to use all available hearing to acquire speech and oral language. This is based on the principle that most deaf and hard-of-hearing children can be taught to listen and speak with early intervention and consistent training to develop their hearing.

Auditory-Verbal Approach: The focus on this approach is to use all available hearing to acquire speech and oral language. The Auditory-Verbal approach promotes listening and speaking through individual therapy using parents as the primary facilitators for language development.

Auditory Training: Training a person with hearing loss to make the most of their hearing. This involves the use of technology (hearing aid, cochlear implant, other assistive listening device) and specialized training to help the child recognize and interpret sound.

Behavioral Observation Audiometry (BOA): A hearing test where the audiologist watches the baby's face and changes in behavior in response to sound to determine what the baby hears. The audiologist is trained to look for the baby to do things such as change his/her sucking behavior, widen his/her eyes, or search for the source of the sound.

Cochlear Implant: A surgically implanted device that replaces the function of a damaged or abnormal inner ear by providing electrical stimulation directly to remaining nerve fibers.

Conditioned Play Audiometry (CPA): A hearing test used for young children. In this method a child is taught to respond to sounds presented by an audiologist in a controlled testing

environment by completing a task such as dropping a block into a bucket. Once the child shows that he/she understands the game, it is possible to use the response to determine if a child hears sounds at lower levels to assess the extent of his/her hearing loss.

Decibel (dB): A measure of the intensity of sound that we interpret as loudness. As part of a hearing evaluation, the audiologist measures at what dB level a child hears certain sounds.

Electrodes and Electrode Array: A surgically implanted part of the cochlear implant. The electrodes receive electrical energy from the speech processor to stimulate the remaining nerve fibers of the cochlea.

Evaluation Process: A presurgical assessment comprised of a battery of medical and hearing tests conducted to determine whether a patient will be an appropriate candidate for a cochlear implant.

Frequency: The physical property of sound that we interpret as pitch. Sound is caused by airwaves which vibrate the eardrum. Frequency refers to the number of vibrations per second in the sound. Faster rates result in higher pitch.

Initial Stimulation: The initial stimulation takes place 2-3 weeks after surgery. During the initial stimulation your child will receive the external equipment. Each implant must be specifically programmed, or “mapped”, for each individual patient. Our audiologist is the person who programs the device. Programming the sound processor involves working with your child to develop unique sets of intensity levels for each frequency (pitch).

Mapping (programming): Involves adjustments to the speech processor through a computer to optimize the patient’s ability to hear with the implant.

Parent-Infant Program: Education for parents and intervention for infants and toddlers that supports the goal of learning language. Parents learn the developmental stages of language and how to effectively expose their children to language.

Residual Hearing: The amount of usable hearing that a hearing-impaired person has.

Sensorineural hearing loss: Hearing loss that affects the hair cells of the cochlea (inner ear), preventing the transmission of sound to the auditory nerve and brain.

Speech Processor/Sound Processor: An external part of the cochlear implant. Its purpose is to analyze the sound signal picked up by the microphone. It uses a selected speech coding strategy to change this information into a code to deliver electrical energy to the implanted electrodes.

Speech Coding Strategy: The formulas used by the speech processor to translate pitch, loudness, and the timing of sound into the signals the implant sends to the cochlea.

Speech Perception Testing: Various word and sentence lists that are presented to your child and they repeat what they hear.

Speech Reading: A rehabilitation process that involves learning to recognize sounds, words, and sentences, on the lips to help understand speech.

Temporal Bone: The bony part of the skull that contains the ear.

Total Communication: A philosophy that uses manual support for spoken English. Signs, gestures, fingerspelling, facial expressions, and body language are used as needed for full expressive communication.

Tympanometry (impedance testing): This test measures the movement of the eardrum and the ability of the middle ear to conduct sound to the inner ear.

Transmitting Coil: An external component of the cochlear implant. It receives coded signals from the speech processor and sends signals to the internal component under the skin.

Visual Reinforcement Audiometry (VRA): During this test, the audiologist directs your child toward a toy that lights up or moves when the child looks at it in response to a sound.

Treatment Plan for Children Receiving Cochlear Implants

The protocol for a given child is designed based on procedures recommended by the manufacturer of the implant device, the age and level of participation of the individual child.

Stage 1 - Initial Contact & Assessment

This stage includes the preliminary determination of possible candidacy for cochlear implantation. Medical and educational records are reviewed and appropriate trial with amplification is initiated when indicated.

Initial testing and counseling regarding the risks and benefits of implantation are also included at this treatment stage.

Stage II - Preoperative Selection and Assessment

This stage includes all preoperative performance evaluations and final determination of the child's candidacy for cochlear implantation. It includes:

Medical Evaluation - To establish the child's health status and determine any medical contraindications to cochlear implantation. CT and MRI scans of the temporal bone are completed and reviewed.

Audiological/Speech Perception Evaluation - To determine the extent to which hearing aids provide benefit. This baseline information of the child's speech perception abilities is used for a comparison of postoperative benefit from the cochlear implant.

****Final selection of a device should occur at least 3 weeks prior to the scheduled surgery date****

Stage III - Surgery, Recuperation, and Prestimulation Training

This stage is estimated at an average of 3-4 weeks. It includes an overnight stay in the hospital and an additional week in the home for recuperation and healing of the incision. The child can generally return to school one week after surgery. A postoperative appointment is scheduled for 1 week after surgery.

Stage IV – Initial Stimulation and Speech Processor Programming (Mapping)

The initial stimulation procedures for children will require approximately 2 hours. This appointment takes place 2 weeks after the surgery. Follow-up programming is scheduled for one-hour sessions at one week, three weeks, and one-month post-initial stimulation.

The mapping/programming process includes measuring and assessing the response to stimulation for each individual electrode. The information collected is used to program a speech processor.

This stage also includes basic instruction in the care and maintenance of the device and assessment of the use of the device outside the clinic.

Stage V – Rehabilitation/Training

Training is a long-term process for children. If a child is not enrolled in an educational program suited for training, then sessions may be conducted more frequently. Follow-up sessions may include testing, evaluation, and reprogramming of the speech processor.

Time during each session is also dedicated to counseling the child and/or parents. Training is completed to the extent possible in conjunction with the child's educational program (see attached "Plan for School Intervention").

Stage VI – Postoperative Evaluations and Follow-up Visits

Periodic evaluations are made of the child's performance with the device and its effect on communication abilities. Evaluations include medical, audiological, and speech perception assessments. During these intervals, adjustments are made to the child's speech processor as necessary to maintain or improve performance with the device.

Required Vaccinations prior to Cochlear Implantation

Proper documentation of up-to-date immunizations and vaccinations should be provided to PENTA for submission to your insurance company. Most insurance companies require vaccinations for cochlear implant candidacy.

Please ensure that your child's immunizations are current and up to date. The following are the pneumococcal vaccination recommendations from the CDC for patients with cochlear implants:

CDC recommends pneumococcal vaccination for all children, including those with cochlear implants.

Children younger than 2 years old with cochlear implants should receive PCV13 according to the Childhood Immunization Schedule <https://www.cdc.gov/vaccines/schedules/hcp/imz/child-adolescent.html>.

If an older child with cochlear implants did not get the recommended doses as an infant and young child, they may need to receive PCV13.

Children 2 years or older with cochlear implants should also receive PPSV23.

Talk to your child's doctor about when your child should get these vaccines. Learn more about what everyone should know about pneumococcal vaccination at: <https://www.cdc.gov/vaccines/vpd/pneumo/public/index.html>

Children should get all recommended doses of pneumococcal vaccines at least 2 weeks before cochlear implant surgery. This will provide maximum protection both during and after surgery.

Children already up to date on these vaccines do not need extra doses before surgery.

Should any questions arise regarding immunizations/vaccinations, please direct those questions to your child's implant surgeon.

Cochlear Implant Checklist

Information for the Insurance Carrier

1. Establish care with CI surgeon
2. Complete imaging (CT/MRI)
3. Provide copy of updated immunizations
 - a. The child should be up to date on all immunizations required by the pediatrician.
 - b. It is recommended that children undergoing cochlear implant surgery receive meningitis (pneumococcal) vaccine in addition to ones required by the pediatrician.
4. Write a parent letter
 - a. The parent letter explains to insurance why the family would like to pursue a cochlear implant for their child.
 - b. This can include difficulties the patient has with current hearing aid technology, academic concerns, etc.
 - c. The letter should include a statement about being committed to attending appointments and taking care of equipment.
 - d. The parent letter can be typed or handwritten but **MUST** include a handwritten signature.
5. Complete case history form (in folder)
6. Auditory Verbal Therapy Intake (see handouts for referral)
7. Hearing aid tutorial
8. Complete unaided and aided testing with Audiologist
9. Complete age-appropriate questionnaire with Audiologist
10. Fill out Release of Information forms for other specialists

The Insurance Process

- A surgery date cannot be scheduled until we have a complete packet of information to submit for approval.
- Insurance submittal once candidacy is determined. (medical necessity letter with supporting documentation)
- Approval received from patient's insurance company. (we cannot proceed until insurance approval is received)

Surgical Process

- Pre-operative counseling with implant surgeon (day prior)
- Surgery Day
- Post-operative appointment with surgeon (1-wk post-op)
- Initial stimulation approximately 2-3 weeks post-surgery

Information may be **mailed** or **faxed (404) 252-1901** to:

PENTA Cochlear Implant Team

5461 Meridian Mark Rd, Suite 130, Atlanta, GA 30342

