

# **UNC Pediatric Cochlear Implant Program**

## **Patient & Parent Information**

**University of North Carolina at Chapel Hill  
Department of Otolaryngology  
Head and Neck Surgery**

**Carolina Children's Communicative Disorders Program (CCCDP)  
Center for the Acquisition of Spoken Language through Listening Enrichment (CASTLE)**



**UNC**  
SCHOOL OF MEDICINE

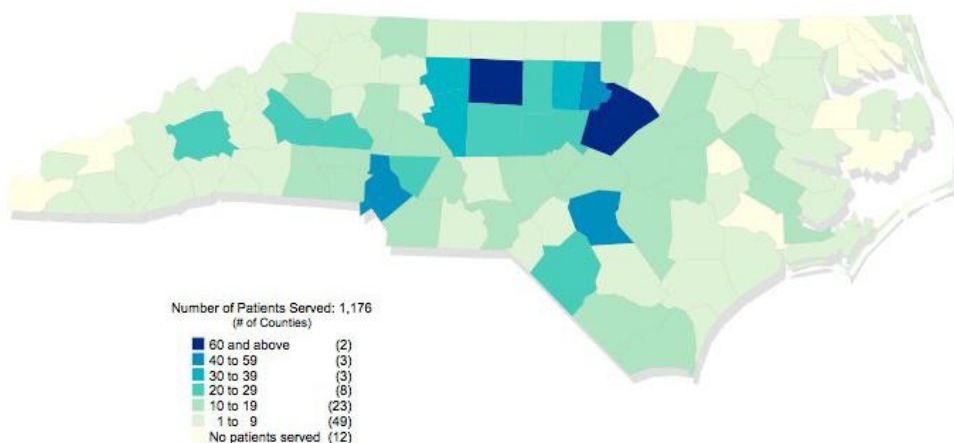


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**The W. Paul Biggers, MD**  
**Carolina Children's Communicative Disorders Program**

Patient Population, June 20, 2006



Source: CCCDP, 2006.  
 Produced By: North Carolina Rural Health Research Program, Cecil G. Sheps  
 Center for Health Services Research, University of North Carolina at Chapel Hill.



## Welcome

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Welcome to The Carolina Children's Communication Disorders Program (CCCDP). The CCCDP is part of the University of North Carolina-Chapel Hill, Department of Otolaryngology at the University of North Carolina Hospital and Clinics. Our pediatric cochlear implant program, which is independent of the adult program, is served by 3 otolaryngologists, staffed by 5 full time audiologists, and is supported by a team of speech-language pathologists, certified auditory/verbal therapists, and teachers of the Deaf and Hard of Hearing in our adjacent CASTLE (Center for the Acquisition of Spoken Language through Listening Enrichment). The UNC/CCCDP/CASTLE organization embodies a very active clinical program, ongoing clinical research, and an educational facility that includes a model oral preschool and training program for therapists and educators.

Your child has been referred to this clinic because he or she may benefit from a cochlear implant. We will assess your child and provide you with the information you need to make a decision about whether a cochlear implant is the right choice for your child. This booklet is your guide to the evaluation process and includes important information that we will review during your appointments. It also includes information on what to expect during and after surgery, and after your child's cochlear implant has been activated. We ask that you bring it to each appointment and keep it as a record of information we discuss.

If you have questions at any time during your child's evaluation, please feel free to inquire. Our goal is to provide you with all the information you need to assist you in this important decision.

We look forward to getting to know you and your child.

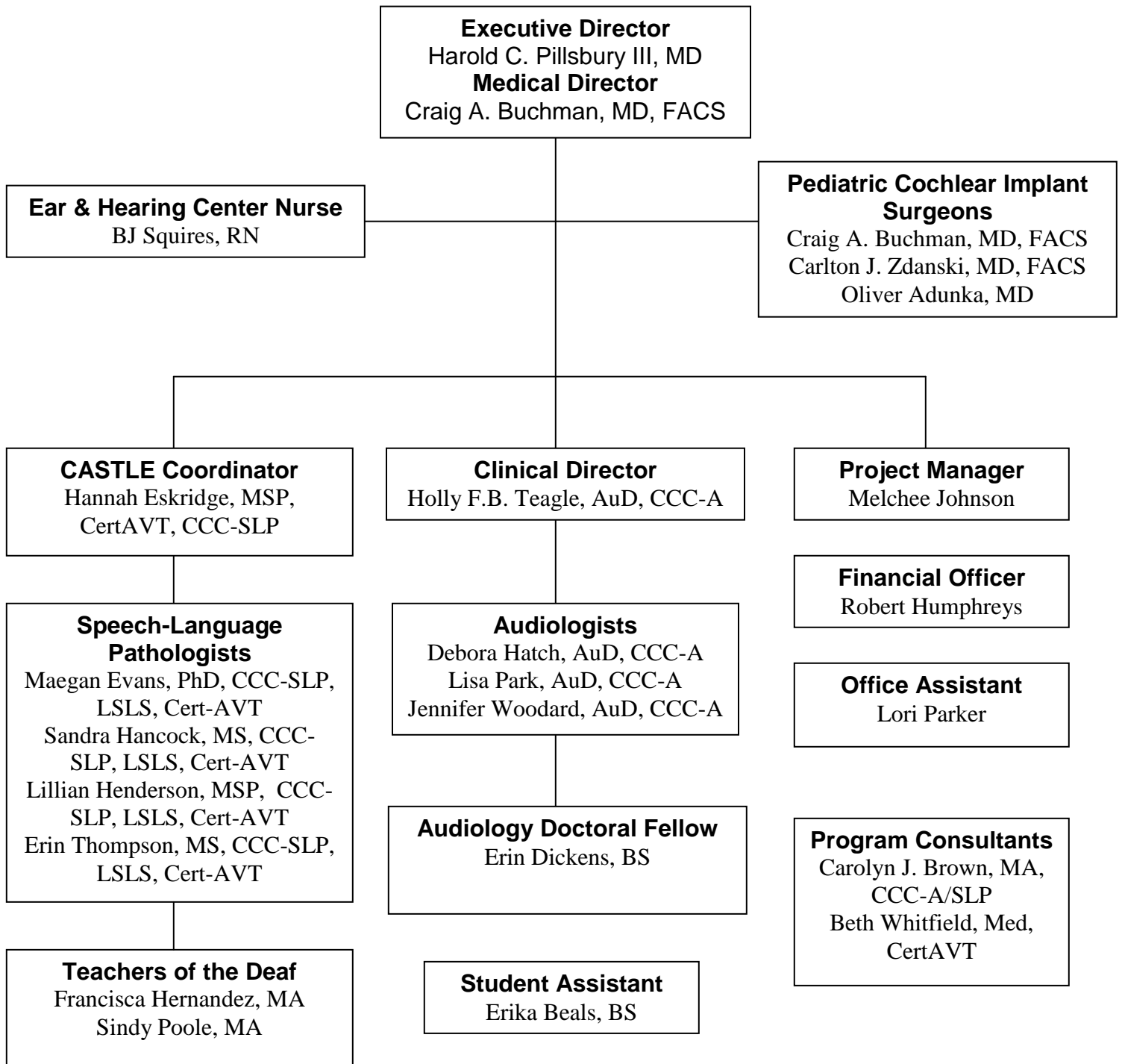
The CCCDP staff



Please visit our website for additional information at [www.uncearandhearing.org](http://www.uncearandhearing.org)



# Cochlear Implant Faculty & Staff





## Evaluation Process

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### The purpose of the Cochlear Implant Evaluation is to:

- Determine CI candidacy
- Provide information to the family
- Answer questions
- Make recommendations

### The Evaluation process consists of:

1. **At least** two audiology appointments to: Appt#1 \_\_\_\_\_, Appt#2 \_\_\_\_\_
  - Obtain medical and educational history
  - Determine child's hearing status with and without hearing aids
  - Determine child's ability to understand speech with hearing aids
  - Provide information to family about hearing, hearing loss and cochlear implants
  - Discuss parent's perception of and goals for the child
2. A speech and language evaluation to: Appt: \_\_\_\_\_
  - Document child's communication abilities
  - Provide information on speech and language development
  - Acquire information about child's current educational situation and offer support as needed
3. At least two physician visits to: Appt: \_\_\_\_\_
  - Determine medical candidacy for a cochlear implant
  - Investigate cause of hearing loss (genetic testing, MRI or CT scan)
    - Discuss the surgical aspects and risks involved in surgery





## Candidacy

### Who is a Cochlear Implant candidate?

Cochlear implants are recommended when a person cannot obtain sufficient hearing from hearing aids to rely on listening for communication. Years of research and clinical experience have contributed to the development of guidelines for determining when a cochlear implant should be recommended. The Food and Drug Administration (FDA) approves the use of cochlear implants for children who meet the specified criteria. Insurance companies often follow these guidelines when determining if the cochlear implant is a covered expense.

#### General Criteria

- Children at least 12 months of age
- Children with severe-to-profound hearing loss
- Children who are healthy enough to undergo the cochlear implant surgery
- Children whose families are motivated to use listening for communication



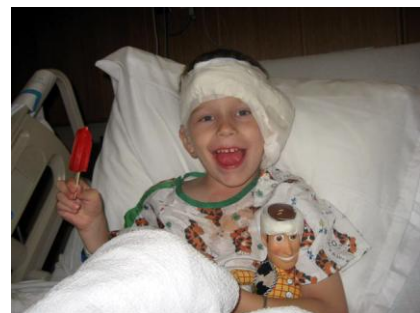
#### Younger children

- Lack of benefit from appropriately fit hearing aids that are worn consistently on a full time basis
- Lack of progress or a plateau in auditory development



#### Older children

- 30% or less word identification on standard tests when presented at a normal conversational level in the best-aided condition and without lipreading cues





## Counseling Topics

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### The CCCDP financial assistance program

### The ear and the audiogram

- How the normal hearing ear functions
- The cause and site of the child's hearing loss
- What is an audiogram?
- The child's degree of hearing loss

### Cochlear Implants

- What is a cochlear implant?
- Who is a candidate for a cochlear implant?
- The three cochlear implant manufacturers
- The evolution of cochlear implant technology, past and future
- Maintenance, warranties, costs and insurance

### What to expect from a cochlear implant

- Benefits for hearing, speech & language, educational & social development
- Factors that affect outcome
- The importance of therapy and the educational setting
- Need for sustained family commitment to therapy and regular follow-up

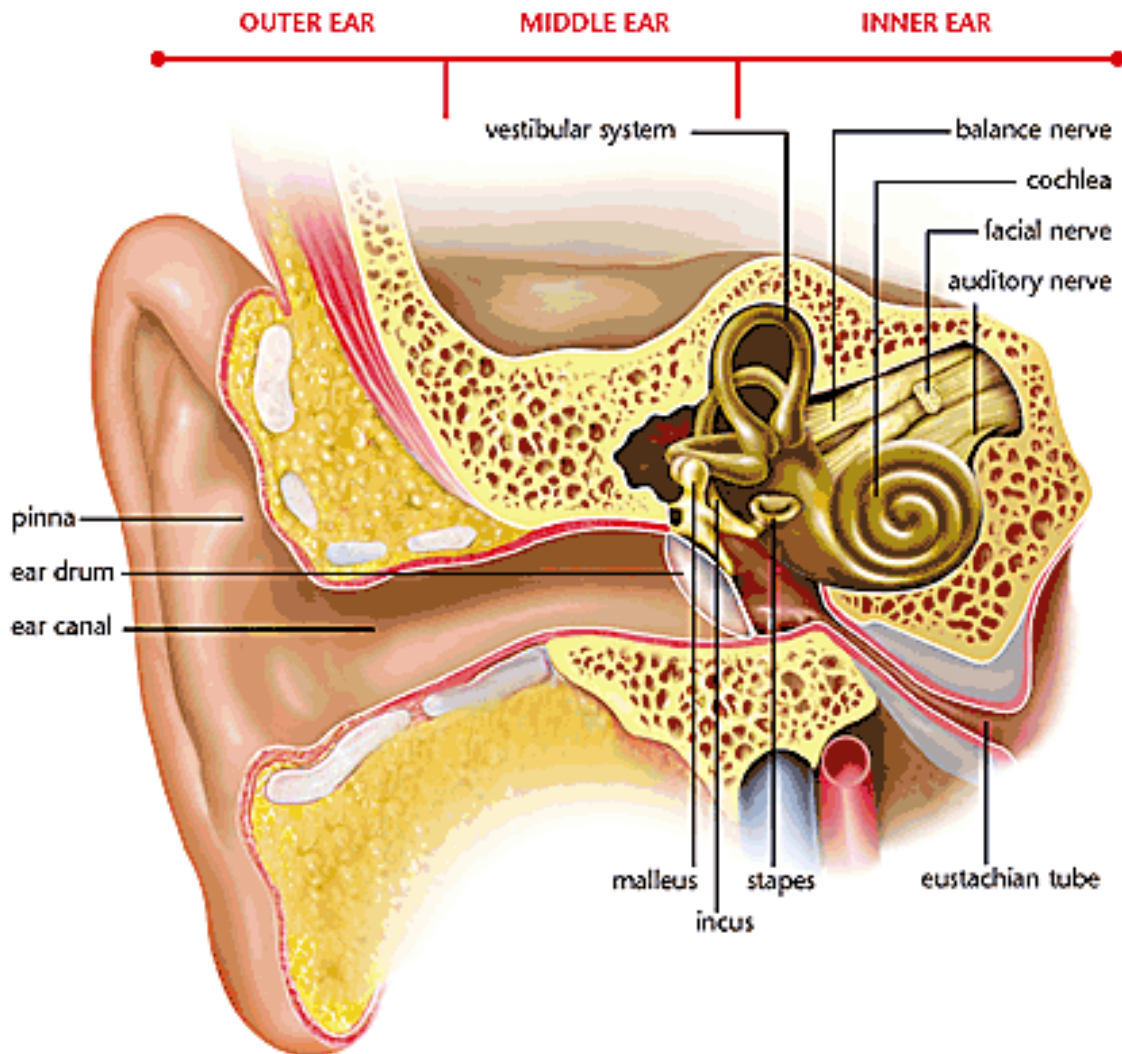
### Medical and surgical concerns

- The surgical procedure
- Risks
- What to expect before and after surgery
- Precautions after surgery: medical issues and activities
- Meningitis

### The initial stimulation and follow-up Audiology visits

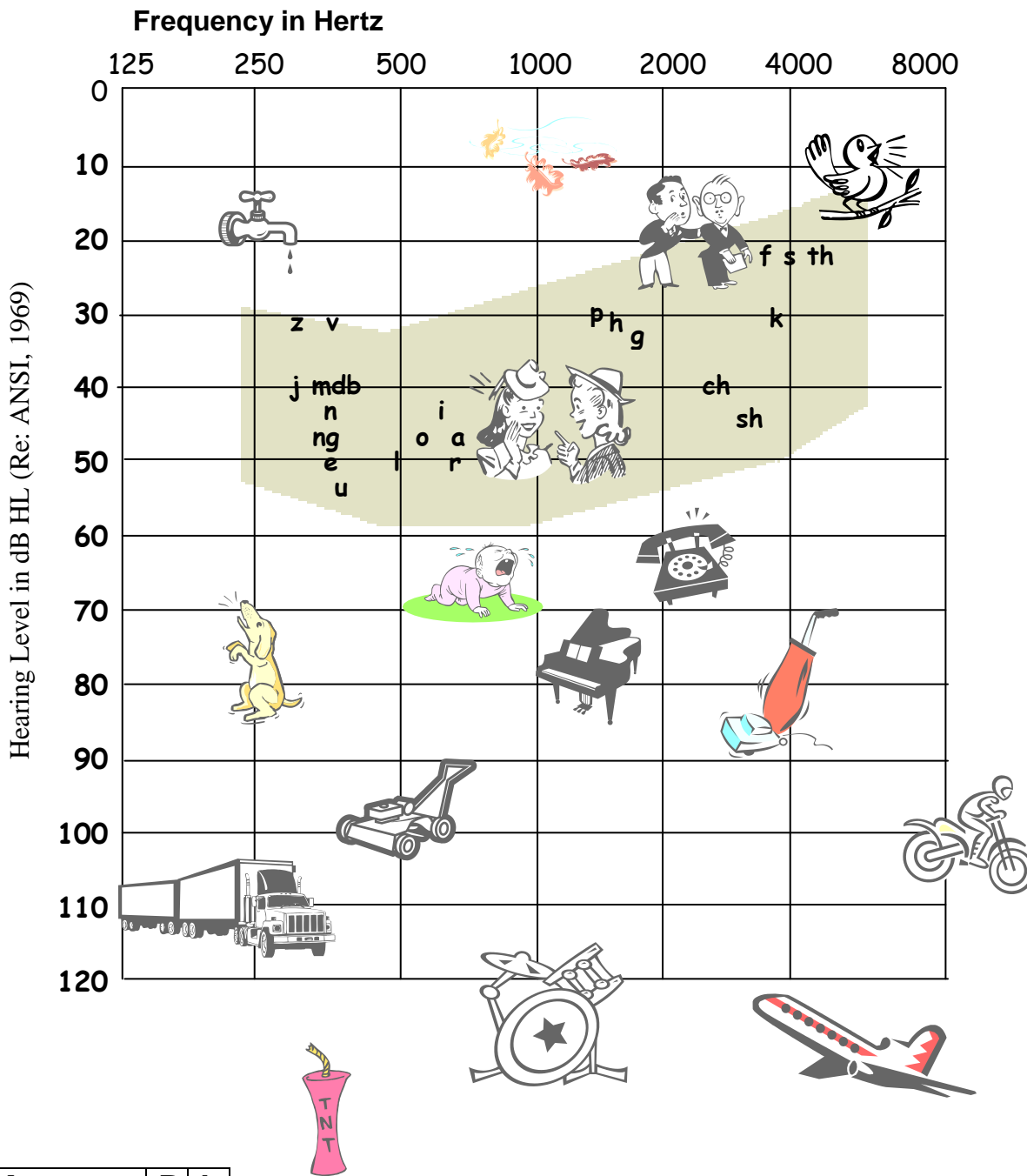
- What to expect and who should attend
- Follow-up appointment schedule
- Considerations of time, travel and other expenses







# Familiar Sounds Audiogram



Key:	R	L		
Air Conduction Unmasked	○	×	Cochlear Implant	C
Air Conduction Masked	△	□	Hearing Aid(s)	A
			CI + Hearing Aid	B
No Response	▶	◀	Aided FM	F

Adapted from Downs, M., & Northern, J. (2002). Hearing in Children (Vol. 5). Baltimore: Lippincott, Williams, and Wilkins.

Conversational speech 6 feet from talker.



## Evaluation Checklist

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### Audiology

- Case History
- Consent Form
- Grant Application
- Unaided Audiogram
- Aided audiogram
- Appropriately fit Hearing Aids for at least 3 months
- Basics of hearing, hearing loss, hearing aids and cochlear implantation
- ABR/OAE
- Speech perception assessment
- CI Devices
- Follow-up schedule

### Speech Pathology

- Speech and Language Evaluation
- Therapy/school services optimized
- Completion of therapy trial if needed
- Completion of other evaluations if necessary

### ENT Physician

- ENT appointment
- MRI/CT
- EKG
- Healthy ears
- Meningitis Vaccine recommendations
- Surgery Procedure and Risks

Once all aspects of the evaluation are complete and it has been determined that your child is a cochlear implant candidate, one final appointment before surgery will be scheduled at the CCCDP to review a **Candidacy Profile**. This is a summary of factors that affect outcome with a cochlear implant and includes the information obtained from the child and family. It helps identify areas that can be impacted by change and helps families develop realistic expectations for their child's use of an implant.

Once the decision is made to proceed, the ear to implant and the device brand and style are chosen. Surgery can be scheduled and plans for follow up appointments can be made.





## Device Information

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There are 3 cochlear implant companies on the market today:



Advanced Bionics Corporation ([www.bionicear.com](http://www.bionicear.com))

Cochlear Corporation ([www.cochlearamericas.com](http://www.cochlearamericas.com))

Med-El Corporation ([www.medel.com](http://www.medel.com))

Cochlear implants systems are made up of internal and external components that work together. The design of the internal device and external components may look different, but they function very similarly. There is no definitive evidence that one implant system provides better results than another.

We will review each cochlear implant system during your appointments. Please consult the websites or the booklets provided for more detailed information.

## Device Warranty

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Advanced Bionics, Cochlear Corporation and Med-El offer a **3-year warranty on the external sound processor**, microphone and headpiece. Most cables are covered by the warranty, although some are not depending on the device configuration. Warranty policies go into effect from the day of initial activation. A one-time replacement for loss or accidental damage (beyond repair) is available during the user's initial 3-year warranty period. Warrantied items are replaced due to "normal wear and tear" only.

For coverage after the 3-year warranty expires, service contracts can be purchased from the manufacturer. To supplement this, or in place of this, loss and damage insurance policies are available through Ear Service Corporation (ESCO). Some families choose to cover the hardware through homeowner's insurance policies as well. Proper care and storage will affect the durability of the external hardware. The better the hardware is cared for, the less chance of encountering problems. Insurance providers may pay for out of warranty repairs, but coverage varies.

Cochlear implants are man-made medical electronics. Although the internal devices are designed to withstand long-term use, it is unlikely that they will last a lifetime. All manufacturers offer a 10-year warranty for the internal portion of the cochlear implant system. This policy goes into effect the day of surgery. Internal devices may fail due to electronic malfunction or due to a direct blow to the head. For this reason, we recommend parents carefully consider allowing their child to participate in "high risk" activities, such as contact sports or bicycling or rollerblading without a helmet.

Cochlear implant manufacturers track the life of their implants as a number called *Cumulative Survival Rate* (CSR). This percentage is tracked by the device model, number of recipients and years that it remains in use. This information is available to the general public upon request.



## Pre-Surgical Information

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- A surgery scheduler will call you with your pre-op date and time; **PLEASE make sure your contact information remains current in the UNC hospital system**
- At least 2 weeks prior to surgery date contact the ENT Department Financial Counselor, Patricia Longest, at (919) 966-7491 to confirm that surgery is APPROVED/COVERED.
- The day before surgery a scheduler will call you to confirm your surgery time
- Report any signs of illness or temperature that occur within 3 days prior to surgery to the ENT office (919) 966-6484
- Do not give your child aspirin or aspirin containing products within 2 weeks prior to surgery as it acts as a blood thinner
- Your child should have nothing to eat after midnight the day before surgery and only limited clear liquids the day of surgery
- Cochlear implant surgery typically lasts 3-4 hours. Children are usually discharged the day of surgery but parents should come prepared to stay overnight in the event that your child is not discharged for unpredictable reasons
- Your child will wear hospital pajamas for the surgery but bring clothes to wear home. A shirt that buttons or zips up the front is optimal as the bandage will be too large for a pullover type shirt
- A nurse will teach you how to care for the incision and dressing at home. Keep the area clean and dry until your child returns to the doctor to have the stitches and bandage removed about 7 days after surgery.
- Your child will see the surgeon for a post-op check of the incision approximately one week after surgery. However, if you have any concerns about the incision, call the ENT office immediately at (919) 966-6484.
- Initial stimulation of the device will take place approximately 4 weeks following surgery. Your child may continue to wear his or her hearing aid in the opposite ear if desired. Discuss this with your audiologist.





## Risks of Surgery

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Your surgeon will discuss these risks with you in as much detail as you desire

- Risks associated with cochlear implant surgery
  - Loss of residual hearing in the implanted ear
  - Increased risk for meningitis
  - Facial nerve stimulation/involuntary facial movement
  - Inflammation/extrusion
    - Soreness, redness or breakdown of skin in area around internal device, which may necessitate additional medical treatment, surgery and/or removal of device
  - Failure of surgery, possibly requiring removal of device
  - Failure of implanted components, possibly requiring removal and replacement
    - Component malfunction may decrease the number of available electrodes for programming purposes; may also result in perception of odd or uncomfortably loud sounds
  
- Risks associated with any ear surgery
  - Numbness/tenderness around implant site
  - Neck pain
  - Facial nerve paralysis
  - Taste disturbance
  - Perilymphatic fluid leak
  - Dizziness (vertigo)
  - Tinnitus or “ringing in the ears”
  - Local complications such as blood, fluid or infection at the site or close to the site of surgery
  - Skin reactions (rashes)
  
- General risks
  - Postoperative pain, scarring, bleeding and infection
  - Anesthetic risks associated with the heart, lungs, kidneys, liver and brain





## Meningitis Vaccination Information

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Bacterial meningitis is a serious infection of the brain and the fluid that surrounds the brain. Bacterial meningitis is a life-threatening infection. Individuals who have a cochlear implant are at increased risk for bacterial meningitis. Although this risk is small, it is important for children and adults with a cochlear implant to be vaccinated against the bacteria that can gain entry into the brain and commonly cause bacterial meningitis. Two types of bacteria have produced the vast majority of cases of meningitis after cochlear implantation: *Streptococcus pneumoniae* ("Pneumococcus") and *Haemophilus influenzae* type b ("Hib").

Cochlear implant users and their families should be aware that vaccines against pneumococcus ("pneumo" vaccine) and Hib are widely available. These vaccines strengthen the body's ability to protect against the common causes of bacterial meningitis. Some infections with pneumococcus are now not treatable with routine antibiotics. This is another reason for being sure to get vaccinated.

### "Pneumo" Vaccines

There are two types of pneumococcal vaccine, Prevnar® for children being vaccinated when they are less than 2 y of age and Pneumovax® for those being vaccinated when they are over 2 y of age. Prevnar® is part of the routine infant immunization schedule in the United States; therefore all children should have received this vaccine in infancy. It is important to verify that your child has received all doses of their Prevnar® series, and if not, to catch up. Now that you or your child has a cochlear implant you should verify which vaccines against pneumococcus you or your child has received and obtain additional doses if you are not fully immunized. Age at the time of vaccination will determine which type of pneumococcal vaccine should be received:

- Children under the age of 2 y: Vaccination with the Prevnar® series followed by Pneumovax® when the child reaches 2 y of age. (Pneumovax® is not effective in children under 2 y.)
- If an adult or child did not receive Pneumovax® before their implant surgery, it is important for them to receive this vaccination now.
- The sooner the vaccine is given the sooner you or your child will be protected.
- It is never "too late" after surgery to benefit from Pneumovax®.
- Second doses of Pneumovax: If it has been 5 or more yrs since the initial Pneumovax® vaccine, discuss a repeat vaccine with your physician. A second dose of Pneumovax® may provide additional coverage for some individuals, including young children and adults over the age of 65.
- Children 2 to 4 y of age: Complete the Prevnar® series if not fully vaccinated. Vaccinate with Pneumovax® at least 2 mos after the last Prevnar® dose.
- Children 5 y and older and all adults: Initial Pneumovax® vaccination



Most people receive vaccinations such as Prevnar and Pneumovax from primary care providers such as pediatricians, internists, or family physicians. Further information on the availability of vaccinations is available through general medical clinics, sponsored state and local government, and by hospitals. Your cochlear implant center can provide more information.

### **Pneumococcal Conjugate vaccine 13 (PCV13)**

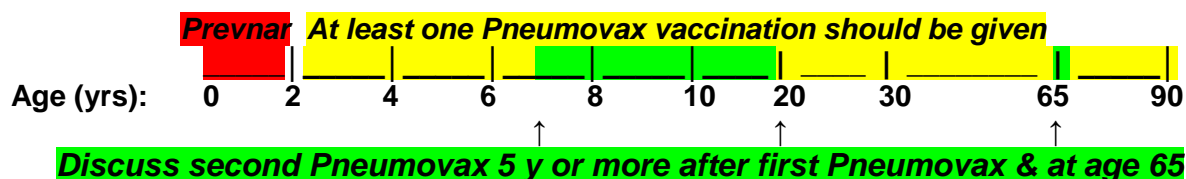
The newest pneumococcal conjugate vaccine (PCV13) protects against the 13 most severe types of the 90 different types of pneumococcal bacteria. This is an update to PCV7 and children will need to have their immunizations updated in order to receive protection against the 13 strains.

- Children under two years should receive PCV 13 as a series of 4 doses.
- Children between 2 and 5 years who have not completed the PCV7 or PCV 13 series before age 2 should get one dose.
- Children between the 2nd and 6th birthdays who have a cochlear implant should get 1 dose of PCV 13 if they received 3 doses of PCV7 or PCV13 before age 2, or 2 doses of PCV13 if they received 2 or fewer doses of PCV7 or PCV13.
- Children ages 6-18 who have a cochlear implant should receive a dose of PCV13, even if they have previously received PCV7.

Further information is available from this CDC website:

<http://www.cdc.gov/vaccines/pubs/vis/downloads/vis-pcv.pdf>

### **Timeline of Pneumo Vaccines:**



### **Follow-up Care**

Cochlear implant users and their families should also be aware that vaccinations do not eliminate the risk of meningitis. Children and adults with cochlear implants who develop a middle ear infection (otitis media) or a fever of uncertain cause should seek medical treatment and monitoring until the infection resolves. **Infections in a child or an adult with a cochlear implant should be taken seriously.** Untreated middle ear and other infections may spread to produce meningitis.

In addition, if an ear with a cochlear implant develops a discharge from the ear canal, or produces unusual ear symptoms or a watery nasal discharge, it is important to have that ear examined by the cochlear implant surgeon or another suitably experienced ear surgeon.



## The Profile

At your final visit, we will review the Candidacy Profile with you. This is a summary of factors that affect outcome with a cochlear implant and includes the information obtained from the child and family. It helps identify areas that can be impacted by change and helps families develop realistic expectations for their child's use of an implant. It's not intended to be a grade, but a tool to open communication about how the team can increase your child's chances of achieving spoken language. The items we review are as follows:

<b>Team Impressions of Factors Important to Implant Use and Success</b>	<b>No Concern:</b>	<b>Mild-Moderate Concern:</b>	<b>Great Concern</b>
CHRONOLOGICAL AGE	< 2 years	2 years to 4 years	> 4 years
DURATION OF DEAFNESS			
DEVELOPMENTAL MILESTONES			
MEDICAL <ul style="list-style-type: none"> <li>• Non-Otological</li> <li>• Otological</li> </ul>	Good general health	Health concerns that require attention & time but do not affect rehab process or device use i.e.: cardiac issues, occasional seizure or active airway disorders	Considerable health concerns that affect child's attention, ability to speak, or consistently use device, i.e. airway disorder or frequent seizures
	Cochleae are normal and patent	Minor malformation (EVA, Mondini), extensive middle ear disease, cranofacial abnormalities	Major malformation (common cavity, hypoplastic cochlea, absent semicircular canals)
ASSOCIATED DISORDERS	No disabilities other than deafness	Blindness, oral motor disorder, sensory integration issues, learning disabilities	Global developmental delay, 2 or more mild/moderate handicapping conditions
AUDIOLOGY <ul style="list-style-type: none"> <li>• Test Reliability</li> <li>• Hearing Aid Use</li> <li>• Hearing Aid Benefit</li> <li>• Use of Residual Hearing</li> </ul>	Good test reliability	Fair test reliability	Poor test reliability
	History of consistent hearing aid use.	Limited hearing aid use (> 50%)	No history of consistent use
	Little or no hearing aid benefit	Some hearing aid benefit	Excellent hearing aid benefit
	Maximizing current auditory potential	Limited progress with residual hearing	No benefit from residual hearing
SPEECH PATHOLOGY <ul style="list-style-type: none"> <li>• Formal Language System</li> <li>• Use of Voice/ Oral Motor</li> <li>• Desire to Communicate</li> </ul>	Formal language system in place: appropriate non-verbal communicative intent	Formal language system emerging; delays in primary communication	No formal language system in place
	Consistently uses voice/ appropriate oral motor development	Requires occasional cues to voice/ mild oral motor delays	Absent use of voice / significant oral motor delays
	Age appropriate attempts to communicate	Moderate intervention to engage child in appropriate communication	Maximum therapist intervention needed to elicit appropriate attention/ communication from child



<b>FAMILY SUPPORT</b> <ul style="list-style-type: none"> <li>Family Structure/Support</li> <li>Parents Participation in Educational Process</li> </ul>	Family communicates with child effectively/ effectively coping with parental stress	Some family members communicate with child effectively; moderate parental stress/ occasional missed appointment	Family does not communicate with child effectively /severe parental stress/ past history of noncompliance
	Parents actively engaged in child's therapy/educational program; able to understand educational system/ (IEP/IFSP); strong advocacy skills	Parents demonstrate some involvement in therapy; beginning knowledge of educational system; potential advocacy skills	Parents do not participate in therapy; little understanding of educational system; appears to have poor advocacy skills
<b>EXPECTATIONS</b> <ul style="list-style-type: none"> <li>Parent</li> <li>Child</li> </ul>	Realizes CI will not restore normal hearing; parental agreement about implant; family has a plan for rehab	Believe child will move to a mainstream setting with no support services; expectations are inflexible; family has no plan for rehab	Believe CI will restore normal hearing/ solve any other medical issues
	Realizes CI not corrective & will need therapy	Believes will not need help using CI	Believes CI will restore normal hearing
<b>INTERPERSONAL SKILLS/ INTERNAL MOTIVATION</b>	Child's behavior typical for age; effective parental control of behavior; child demonstrates desire to learn	Inconsistent engagement in therapy sessions; sporadic parental control of child's behavior; some desire to learn	Severely hyperactive; aggressive or defiant behavior; poor parental control of child's behavior; consistent disengagement in therapy sessions
<b>EDUCATION</b> <ul style="list-style-type: none"> <li>Current Educational Placement</li> <li>Future Educational Placement</li> <li>Availability of Support Services</li> <li>Staff CI Training</li> </ul> (Ms=mainstream, Tx= therapy, Ed= education)	Auditory oral class or oral MS; appropriate Ed. environment	TC; special ed	ASL; self-contained class; no auditory tx
	Auditory oral class or oral Ms; appropriate Ed environment	Limited auditory based intervention; special ed	ASL/ TC self-contained class; no auditory tx
	Program provides appropriate auditory based intervention	Program will provide moderate levels of auditory based intervention	Program will provide minimal amounts of auditory based intervention
	Teachers and therapists with training and experience in the development of spoken language through listening and CI	Teachers and therapists with beginning training and experience in the development of spoken language through listening and CI	Teachers and therapists with no training or experience in the development of spoken language through listening and CI





## Initial Fitting & Follow-up Information

### Initial Fitting

**This visit is typically two hours in length and has the following goals:**

- Fit the sound processor, microphone, headpiece, harness
- Create a “first-pass” map or program that is comfortable for the child. Additional maps will also be created for the child to try prior to the next clinic visit
- Counsel family regarding device operation, troubleshooting, equipment care and maintenance
- Complete Product Registration and Warranty information

**To achieve those goals:**

- The session will begin with measurements of the integrity of the internal device (impedances)
- Depending on the child’s age and previous hearing experience, subjective or objective measurements will be used to create the maps
  - If Subjective Measurements are possible, individual channels will be stimulated until the child reacts or otherwise indicates that he or she has “heard” something
  - If Objective Measurements are necessary, the implant software is used to measure the auditory nerve’s response to stimulation. The child need not actively participate in this process.
- Once the processor has been programmed and as the child becomes accustomed to and accepting of wearing the device, attention will turn to the caregivers and imparting knowledge regarding the use, care and maintenance of the device

### Follow Up Appointments

- Because of the rapid adaptation of the auditory system, numerous mapping changes are necessary in the first year of cochlear implant use. For this reason, we have established the following schedule after surgery.
- Initial fitting (3-4 weeks after surgery)
- From Initial Fitting:
  - 2 weeks
  - 5 weeks
  - 9 weeks
  - 3 months
  - 6 months
  - 9 months
  - 1 year
- Children are then seen at six month intervals until they are school age and then they are seen once per year
- Parents may schedule additional appointments as needed.





## Initial Stimulation & Orientation Checklist

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### Equipment

- Device operation & troubleshooting
- Equipment care and maintenance
- Retention
- Battery use and life
- Accessories
- Ordering replacement parts or new equipment
- ESCO insurance or homeowner's policy coverage
- Medic- Alert

### Documents to be signed and/or dispensed

- Device registration card
- User manual
- Pocket reference card/booklet
- Identification card for travel
- Medic alert brochure
- ESCO brochure
- Teacher troubleshooting references – available online

### Recommendations

- Read user manual prior to next visit
- Work towards wearing device all waking hours
- Monitor child for comfort, sound awareness
- Stimulate child with talking, reading, singing
- Check magnet site, if redness or swelling is observed, contact your ENT surgeon immediately.
- Track battery usage – rechargeables should last all day, disposables ~2-3 days
- Work through programs as discussed with audiologist



## What to Expect at Hook-up

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About 4 weeks after surgery, after the incision has healed, the child returns to the implant center to be fitted with the external parts of the device and to have the speech processor “mapped” or programmed. For children, the fitting may continue over a period of several months. During the first months of implant use, as hearing improves, reprogramming is performed often; thereafter, fewer visits are required.

To begin fitting, the speech processor is placed behind the ear, similar to how a hearing aid is worn. The transmitter is placed on the side of the head behind the ear and is held in place by a magnet. The transmitter is connected to the speech processor by a cable.

Next, the process of programming, or mapping, the speech processor begins. To begin the programming, the speech processor is connected to a computer. One by one, the individual electrodes, each of which carries a slightly different frequency or pitch, are stimulated. If developmentally appropriate, the child will play a game to indicate when a sound is heard. For younger children, parents and audiologists observe the child’s behavior for any evidence that sound is heard.

Finally, levels where sound is heard for each electrode are programmed into the speech processor by the audiologist. In doing so, she creates a “map” which allows the child to detect sounds but prevents them from being too loud. At this point, the audiologist will activate the microphone so the child will pick up sounds in the environment. To begin with, the audiologist will have the volume turned all the way down to ensure that the child’s first experience with sound is not too loud. The audiologist will slowly turn up the volume while watching the child’s behavior. Children’s responses vary and responses can range from crying, to smiling, to no response at all.

### Learning to Use the New Sound

Hearing speech through the implant may sound unnatural at first. However, over a period of time, the sounds will become familiar. Children who have never heard may require a longer time period to adjust to sounds.

Children benefit from supportive services that teach them how to use their cochlear implant. Working with an audiologist, speech-language pathologist, early interventionist, or teacher of the hearing-impaired will help the child identify sounds and improve. Therapy and training will focus on helping the child speak more clearly, and instructions will be given for practicing at home. After the implant, therapy for children is essential. Without it, a child will obtain only partial benefit from the device because it merely makes new sounds available. The child must be taught how to understand the sounds, which will eventually translate into improved speech and language. Children must learn to associate meaning with unfamiliar sounds. Therapy services will be required for an extended period of time, often throughout childhood. A child’s performance usually continues to improve with time and training. Children should return to the implant center at least every 6-12 months for monitoring and program adjustments to the speech processor.

### Expectations

Before children with normal hearing learn to speak, they spend over a year listening to sounds around them. Speech and language develops with time and experience. Be patient and go from the simple to the complex when working with the new cochlear implant user. Talk to the child normally, and read and enjoy picture books together. Children’s stories on tape, accompanied by follow-along books, are good for older children to assist them in learning the sounds and rhythms of speech. Your therapist can guide you to learn activities for practicing at home. Expect the cochlear implant to provide useful sound and improved hearing with practice and patience.



## What Things Cost

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The surgery, internal device, and external equipment costs a total of approximately \$70,000. This cost will be born by Medicaid or your insurance. As good stewards of these funds, we want you to be aware of the costs and responsibilities for this equipment.

All external parts are covered under manufacturer's warranty for three years for normal wear and tear, with the exception of the remote assistant from Cochlear and any rechargeable batteries, which carry a one year warranty. If you lose a piece of equipment, the manufacturer will replace it one time within those three years. If you lose equipment again, it will be your responsibility to replace it.

After the three year warranty is over, you will be responsible for paying for replacement parts. Medicaid and insurance plans sometimes cover these charges, as does the CCCDP grant program. It is your responsibility to be sure of what will be covered. It will be in your best interest to purchase an extended warranty (called a service contract) when the warranty is expired, either through the implant manufacturer or a private party. It is imperative that the device be covered for loss and damage after the warranty has expired. **Medicaid and the grant do not cover lost equipment.**

You will receive two complete sets of equipment, so that your child will always have backup equipment and should never be "off the air." Please be certain that both speech processors always contain the most current program and are functioning well. Bring both to all CCCDP appointments.

Congratulations on your choice to have your child receive a cochlear implant. This is a very exciting and emotional time and we are honored to share it with you. Please use this guide to keep yourself aware of the equipment your child is using and the costs of replacing the equipment. We want to help ensure that your child is hearing to their potential every step of the way.

Sincerely,  
The CCCDP Staff



## Average Equipment Costs

### The “Must Have” Parts

Speech Processor (the part that contains the programs)	\$7,000-\$7800
Battery Rack	\$180 (Cochlear) - \$265 (Med EI)
Battery Rack Cover	\$3 (Med EI) - \$100 (Cochlear)
Disposable Batteries	\$190 (pack of 50 cells)
Rechargeable Batteries	\$125 (Med EI) - \$165-\$200 (AB) - \$220 (Cochlear)
Charging Kit	\$250 (Med EI/AB) - \$350 (Cochlear)
Headpiece Cables	\$32 (Med EI) - \$95 (Cochlear)
Coils	\$195 (Cochlear) - \$295 (Med EI)
Cable/coil Headpeice (AB)	\$250
Earhooks	\$12 (Med EI) - \$35 (Cochlear) - \$75 (AB)
Microphone Covers (Cochlear only)	\$25
Magnets	\$0 (AB/Med EI) - \$35 (Cochlear)

### The Accessories

Huggies/Snugfits/Mic Locks	\$5 - \$36
Personal Audio Cable (for MP3 Players/iPods)	\$50 (AB), \$63 (Med EI), \$150-\$200 (Cochlear)
Monitor Earphones	\$50 (Cochlear) - \$295 (Med EI)
“Off the Ear” Pediatric Options	\$250 (AB) - \$350 (Cochlear/Med EI)
LiteWear fixing kits (Cochlear)	\$50
Dry-n-store	\$75
Remote (Cochlear and Med EI)	\$200 (Med EI) - \$500 (Cochlear)



## **Oh No! Something Broke!**

As robust as the equipment may be, at some point in time it will break due to accidents and normal wear and tear. It's easy to get overwhelmed when you learn your child is "off the air," but here are the steps to take when something goes wrong.

1. Before you do anything else, pull out the user guide you got at hook-up and consult the troubleshooting section.
2. If you can't solve the problem yourself, call the manufacturer directly:
  - Cochlear: 1-800-483-3123
  - Med El: 919-572-2222
  - Advanced Bionics: 1-877-829-0026
3. If you're still having a problem, call the clinic at 919-419-1449.

We ask you to call the manufacturer before you call the clinic because it saves a great deal of time and will help get your child's hardware repaired more quickly. If you call us first, we will have to call the manufacturer and they will often have to play phone tag with you to get insurance information and other details.

Whenever you have to make a phone call regarding your child's equipment, be sure you know the serial number of the processor that has the issue, and the names of the parts. It's very hard to help get your child hearing again without specific details.



## Bilateral Cochlear Implantation

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Views on bilateral cochlear implantation have changed significantly in the recent past and it has become more common to implant both ears. If a child has usable hearing and can still benefit from a hearing aid, it may be appropriate to continue hearing aid use in one ear in addition to the cochlear implant in the other ear. This decision is unique to each child.

There are several expected benefits of having bilateral cochlear implants. When properly fit, worn all waking hours and when therapy is utilized to develop audition skills with the new implant, a bilateral cochlear implant recipient could expect the following:

- Improved speech understanding in noise,
- The ability to localize sound
- Never being left without hearing should internal or external components of one CI require repair or fail.

Most major insurance carriers as well as North Carolina Medicaid support bilateral cochlear implantation. Certain criteria must be met in order to be considered a candidate for a second implant. NC Medicaid lists the following criteria:

- Demonstrate successful use of the first device **and**
- Active participation in an appropriate auditory-based intervention program **and**
- Active participation in an appropriate educational program **and**
- Radiographic evidence that contralateral cochlea and nerves are normal **and**
- Demonstration by the patient or family of an ability to care for the equipment needs of two devices **and**
- No evidence of severe physical, psychomotor or cognitive delays **and**
- When at least one of the following applies:
  1. Continued usage of a hearing aid has been unsuccessful, if residual hearing is present,
  2. The first side device is non-functional for medical/surgical reasons and replacement surgery is not an option or
  3. The first side is suspected of having a device failure but still provides some beneficial auditory input or
  4. The recipient develops significant delayed-onset visual impairment

Due to the increasing number of families interested in bilateral CI for their child, the implant team asks that bilateral cochlear implantation be explored after their child has completed a year of implant use with their first device. This allows for greater flexibility in planning for surgeries for children receiving their first implant as well as being able to accommodate the ever-increasing number of those waiting for a second device.



## **Bilateral Cochlear Implantation FAQ**

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### **Q: Why do we need to hear with two ears?**

Listening with two ears is beneficial to people in general. It allows us to know where sound is coming from (localization) and to hear speech better in noisy environments. Speech sounds are louder when we listen with two ears as opposed to one. People with normal hearing naturally learn to integrate sound from each ear. For people with hearing loss, binaural integration of sound is much more difficult, especially if there is a difference between the ears, either in the amount of hearing or the amount of time the ear has been deprived from hearing.

### **Q: What are the potential benefits of two cochlear implants?**

Research in adults suggests that 2 cochlear implants allow people to hear better in noise and localize sound better than those with only one device. However, people with normal hearing still perform these tasks at a much better level than patients with bilateral cochlear implants. The single greatest benefit for having 2 implants is that when one is not working, the other one usually is. Thus, there is much less down time when a device has problems. There are a few large scale studies on bilateral cochlear implants in children. Recently published data suggests that earlier bilateral implantation is better than waiting for future advances in technology because it is increasingly difficult to achieve binaural benefit with an increased interval between placement of the first and then second implant.

### **Q: Does having two implants pose more risk?**

All of the typical risks of cochlear implant surgery must be considered when it comes to making a decision about a second cochlear implant. Clearly, placing 2 devices at the same setting requires a longer anesthetic time and the same risks for each ear with regard to the potential for surgical complications. Operating on 2 ears at the same setting when there is residual hearing will likely render the patient completely deaf before the cochlear implants are activated. It is important to ask if the benefits of bilateral implantation outweigh the surgical risks. When your child received their first implant, the benefit of going from little usable hearing to significant hearing was obvious. With the second implant, benefits are less dramatic and the risks remain the same making the margin between risk and benefit somewhat narrower.

### **Q: All kids with one cochlear implant should really have two, right?**

Not necessarily. It is important to remember that cochlear implants cannot yet transmit all acoustical information to the brain. Some children still have some measurable hearing in their non-implanted ears. For these children, it may be possible to achieve greater benefit by listening with a hearing aid and an implant than with 2 implants.



**Q: Shouldn't we "save" that ear for future technology?**

When parents ask this question, they are typically asking about hair cell regeneration but this may also apply to future implant-related technologies as well. We know that there is a "critical period" for development when the brain is most able to adapt and change to new inputs. We expect that hair cell regeneration won't be a viable prospect in humans for at least 10 years. That means that a baby born today would not be able to take advantage of hair cell regeneration before the critical period of development has passed. Hearing is a "use it or lose it" sensory system and if you are willing to have your child undergo surgery again, it seems reasonable to do it earlier in his or her life rather than later. Having said that, we don't know when it may be "too late" to benefit from the second cochlear implant, but it certainly appears that children who are born deaf and receive the second device before age 8 or 9 seem to obtain greater benefit for the relative risk. These aspects of bilateral cochlear implantation are still being studied. Finally, we don't know what cochlear implants will look like in 30 or 40 years from now. Will future devices be compatible with the currently available electrode arrays? Stated another way, if the device that your child has today fails, will we be able to substitute the newest advanced technology for that which is currently in place? Will manufacturers continue to produce back compatible devices? The answers are unknown.

**Q: Does insurance cover bilateral implants?**

Most major insurance companies now cover bilateral implants for children. For most families, it is not realistic to cover the cost of cochlear implant surgery without insurance support. Recently, North Carolina Medicaid agreed to cover a second implant if the cochlear implant team recommends it based on specific criteria (see page 24 for details). If you are interested in bilateral implantation for your child, the UNC implant team will provide an evaluation and work with you to decide if this is a medically necessary procedure. If it is, we will work with you to provide the necessary information to your insurance company.

**Q: What does the research on children with bilateral implants show?**

There is electrophysiological evidence that congenitally deaf children implanted with their second device after the age of 9 may not achieve the same benefit they get from their first device. Within this clinic, it has been observed that when the interval between the first and second implant is relatively narrow, bilateral benefit is achieved. Children who were born deaf, received their first CI at a young age and then get a second CI as a teenager often have great difficulty adjusting to the new implant.

**Q: What can we expect to gain by implanting the other ear?**

Research has shown us that children who listen with only one ear are at a greater risk for having educational difficulties. One would expect that this is true for children with one cochlear implant. Listening with two ears may help some, but it is important to remember that hearing with an implant is not normal hearing! Children with bilateral implants may function better in noise and may be better able to tell where sound is coming from, compared to having one implant. The newly implanted ear will need time to listen and learn. This means that AV Therapy will be important and it will be a bit like "starting over" with the new ear. Our speech pathologists would like to meet with you and discuss this process and the options for habilitation with a second implant.



## **Bilateral CIs Vs. Bimodal Hearing**

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### **Sequential versus Simultaneous Cochlear Implantation**

Sequential bilateral cochlear implantation is when a patient receives two cochlear implants during two separate surgeries. The vast majority of the pediatric bilateral implant recipients from this clinic received their two devices sequentially.

Simultaneous bilateral cochlear implantation occurs when a patient receives two cochlear implants during a single surgical procedure. The two most common reasons for simultaneous bilateral cochlear implantation in young children are:

- Following a meningitis infection, significant hearing loss occurs and there is a build-up of bony tissue (ossification) within the cochlea. Significant build-up of this bony growth within the cochlea makes it difficult to achieve a complete insertion of a cochlear implant **or**
- Significant bilateral visual impairment is present or is expected to develop, such as in Usher's Syndrome.

### **Bimodal versus Bilateral**

Bimodal hearing is when someone uses a cochlear implant in one ear and a hearing aid in the other ear. Some children still have some measurable hearing in their non-implanted ears. For these children, it may be possible to achieve greater benefit by listening with a hearing aid and an implant than with 2 implants. The reason for this is that the residual hearing, although not good enough on its own, can provide additional information not available through a cochlear implant. These children may gain benefits such as music appreciation and pitch perception that bilateral cochlear implant children cannot obtain.

In the event a unilateral cochlear implant user has no measurable hearing in their non-implant ear, bilateral cochlear implantation may be recommended.



## **COMMUNICATION MODE AND SPECIAL POPULATIONS**

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As cochlear implant candidacy criteria have changed over time, so have the populations that may benefit from its use. Today, children with other developmental delays in addition to hearing loss are being considered as candidates for implantation; their communication goals may be very different from a typically developing child who has the diagnosis of hearing loss. This is an important consideration and expectations for outcome with a cochlear implant should be discussed with the family and CI team. Recommendations may be made for the implementation of Cued Speech, sign language, augmentative communication or other visual support to aid in independent communication. Working on audition skills is equally important however and should be a strong component of habilitation. The goal is for each child to achieve his or her communicative potential. This may mean incorporating some form of visual communication to supplement sound through the implant.



## Who we are and how to contact us

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919-419-1399 (fax)

**CASTLE:** 919-419-1428  
919-419-1399 (fax)

**ENT Clinic:** 919-966-6484  
919-843-9361 (fax)

**Carolina Pointe:** 919-490-3280 (office)  
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# Notes

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Visit our website for more information:

[www.uncearandhearing.com](http://www.uncearandhearing.com)

Last updated 10-17-2011

