

ICIC newsletter

Next ICIC Meeting

Hear Here!

Dear members, the topic of our next meeting has changed. Unfortunately Dr. Remensnyder is unable offer her presentation on the "American with Disabilities Act" at this time. However, we are delighted to present a program that is sure to interest you all:

Maximizing your hearing potential with aural (re)habilitation

*The presenter is our own Tina Childress.
Tina is an audiologist and is also the recipient of
bilateral cochlear implants.*

on

Saturday, November 21, 2009, 2:30 – 4:30 P.M.

at

Morton Grove Park District's Prairie View Center
Dempster & Waukegan
(one block east of Waukegan on Dempster.
Turn north on New England St.)

*Aural (re)habilitation can be as formal as sessions
with a therapist or as informal as reading with your
family - whatever works with your lifestyle!*

*Come and learn some of the basics for setting up
your own program, available resources (many are
FREE) as well as realistic expectations. There will
also be a demonstration on how to use accessories
like direct audio input, Bluetooth, FM systems and
iPods as part of your listening therapy. These tips
and tricks can apply to those adjusting to hearing
loss for the first time or for those who need some
fresh ideas.*

**Real Time Captioning is provided by
"Caption First"**

5K Chicago Walk4Hearing

**Join us on the 3rd annual Chicago
Walk4Hearing**

**Sunday, October 18, 2009
at Lincoln Park, Chicago**

Registration at 9 A.M. Walk starts at 10 A.M.

*There is still time to register to walk
individually or as a team.*

For more information visit

www.walk4hearing.org

The W4H is an important means of increasing public awareness about hearing loss issues and interventions which are available. Last year's walk raised over \$70K and this year's goal is \$85K. To date, sponsors have pledged over \$24K, an approximate 15% increase vs. 2008. With the proceeds from last year's walk ICIC embarked on a Community Outreach program. So far ICIC has contributed to a scholarship fund enabling a young adult to attend the recent HLAA convention, continued as a Bronze sponsor of the W4H, is investigating the purchase of a sound system for its general meetings, and will have a booth at the January, 2010 Audiology convention.

What IS ICIC?

The Illinois Cochlear Implant Chapter (ICIC) offers support and information to cochlear implant recipients, prospective recipients and other interested parties. ICIC is a chapter of the Hearing Loss Association of America. Annual donations are \$25.

*Disclaimer: ICIC neither recommends
nor endorses products, people or
services. Opinions expressed are those
of the individuals, not those of ICIC.*

Minutes of ICIC meeting

July 18, 2009

Edited by Liz Booth

Dr. Robert Battista, Ear Institute of Chicago
Dawn Maniskas, Hinsdale Hospital, pediatric audiologist:

***“Adult and Pediatric Bilateral Cochlear Implants,
Sequential and Simultaneous”***

Dawn Violetto, audiologist:

***“Child’s Voice, an Oral School
for Deaf and Hard of Hearing Children”***

Dr. Battista addressed questions from the audience as technical difficulties were resolved.

1. Auditory brain stem implants are for those who do not have a hearing nerve, often the result of a condition called neurofibromatosis type two. There are benign tumors around the hearing nerves that prevent them from operating properly. You need a functioning hearing nerve in order for a cochlear implant to work. The auditory brain stem implant stimulates the hearing system in the bottom of the brain and the brain stem. A very select group of doctors deal with this type of surgery.

2. The inner ear and the middle ear bones are adult size at birth, however the mastoid bone is smaller in children. The fascia recess, the area where the electrode enters between the eardrum and facial nerve, is adult size at birth. So the surgery on children is the same as surgery on adults. For both children and adults CAT scans and MRIs are important to detect any significant anomalies prior to surgery. Nothing in the internal parts needs to be changed with the CI as the child grows. There is a little excess of wire that will expand as the mastoid gets bigger, so it is built into the system. Cochlear implants are designed to last for 75-plus years.

Dr. Battista began his presentation with an overview of bilateral advantages. There is improved hearing in both quiet and noisy situations. Stereo hearing can help you figure out where sounds are coming from. This is called sound localization. It is simply easier for you to hear if you use both ears. We have to look at the anatomy of the ear to understand why both ears work better than one, whether there are two implants, or one implant and one hearing aid. The cochlear is coiled with a tonotopic arrangement, i.e. high frequency sounds are processed in the bottom part of the inner ear and low frequencies in the inside part. These signals go to the temporal lobe of the brain where we actually hear sound. This too, is tonotopically arranged just like a piano. Nerve fibers from each ear go to both sides of the temporal lobe; basically the wires are crossed. Binaural is both ears processing sound. However, the sound will take longer to get to one side than the other and that delay gives us the ability to figure out where the sound is coming from and also helps us to block noise, the squelch effect.

To further explain this phenomenon Dr. Battista talked about the Baha, a bone-anchored hearing device sometimes used to treat single-sided deafness. The Baha is placed behind the deaf ear and sends the sound through the bone of the skull to the deaf side. Research with the Baha found that single-sided deafness is a real problem because it affects people’s ability to localize sound as well as hear in quiet and in noise.

This was determined around 2002 and that is when research into bilateral cochlear implants really took off. Localization occurs when the sound source is on one side of a person's head. Because the head is in the way, the other ear does not hear the sound as quickly, so there is a bit of a delay. The body is able to pick up that delay and figure out where the sound is coming from. This occurs if the person has hearing in both ears.

Dr. Battista defined the two types of bilateral CI surgery. Simultaneous bilateral implants are put in at the same time, during the same surgery. Sequential means that the second implant is placed either a few weeks or a few months or years after the first implant was placed. Most of the data in this talk today is about the latter.

Dawn Maniskas continued the presentation.

More and more people are obtaining a second cochlear implant or else wearing a hearing aid with a cochlear implant. This supports the belief that two ears are better than one. In addition to localization ability and lateralization ability, you require binaural squelch, or what is called release from masking. Both of our ears take sound and, they not only send the sound up to the one side of the brain, but most of those neuro pathways are going to the opposite side of the brain stem and then up to the opposite side of the brain. Binaural squelch is before sound gets to the brain. When the sound goes into two ears, there is crisscrossing and energy is being collected. The neurofibers are able to determine what types of sounds are going through and which are going to be blocked.

Usually if we are in background noise and can hear higher pitches, we will hear someone who is speaking. If we have normal hearing or if we have balanced hearing in both ears, only the voice will be sent through and the rest of the background noise will be suppressed. If you have hearing in only one ear, everything goes through at the exact same level with no filter system. With two balanced systems, sound going through both ears, you now have binaural squelch.

Neuroplasticity refers to the brain being plastic and morphable, and the younger you are, the more morphable and plastic it is. When you are younger, it is easier for the brain to adapt to a new way of listening and fine tune exactly what you hear.

There is ongoing research with bilateral cochlear implants and the ability to appreciate music. Some of this has to do with the timing aspect. It was found that people in Eastern cultures were not doing as well with cochlear implants as those in the Western cultures because of the timing of the way the language is spoken. This also applies to music. Changes in processing strategies may address this problem.

Under the age of three, a child is more likely to develop speech and language skills at an easier rate than at any other time in life. The goal is to give a child the ability to have access to speech, preferably in two ears, before all of this happens.

So, overall, studies are showing that bilateral cochlear implants and just bimodal hearing in general are going to improve speech understanding abilities and hearing in background noise. However there is a lot of variability in actual results due to reasons for hearing loss, time of hearing loss, etc. It is very difficult to test a baby and ascertain improvement when he/she has not yet learned to talk. However, generally children are doing better with bilateral implants and timing is the key. The sooner you give the brain access to sounds and speech and language, the better you will be when you try to use the sounds. This counters auditory deprivation. Studies are showing that children are doing better with bilateral implants.

Dr. Battista continued by saying that the longer the time between getting a second implant, the greater the difference and variability will be from one side to the other. It is better to have the second implant closer to the time of the first implant. Two implants help you hear better in quiet situations, however the bilateral implants really shine in noise. One ear may have more nerve endings that can be stimulated than the other side, and there is no way for the implant team to know which side is going to be the better side before surgery. So when you have two implants, you are always going to get the better side, if there is a better side.

Dr. Battista again addressed the issue of localization. The length of time to develop localization ability is inverse in proportion to the length of hearing history prior to the first implant. In general sound localization capabilities improve with time. If you get a second implant you have a backup if the device fails or the battery goes out. The term, "use it or lose it," applies here. Think of the hearing portion of the temporal lobe as a muscle. If you do not use it, it will get smaller and not work as well, but if you stimulate it, it will remain robust. With sequential implants the poorer ear is usually implanted first so the better ear can continue to use a hearing aid.

In children, it has been found that it is best to do simultaneous implants or a sequential implant in the second ear within 3-1/2 years for the most gains. Arguments against simultaneous implants include increased operative time, added surgical risks (which are quite low), and loss of residual hearing. In some cases, soft surgery is done where residual hearing may be preserved. Some people are choosing to wait for newer technology. However right now we are only scratching the surface of what the present internal devices can do. All the updates are with the external device, so you can be upgraded at any time without new surgery. It appears that hair cell regeneration is a long way off.

Questions from the audience were taken at this time:

---The second implant does not necessarily have to be the same model or the same manufacturer as the first.

---There are studies that show improved hearing with a second implant being done 17-19 years after the first implant. Binaural benefits can be seen as soon as 1-2 months after activation.

---Most insurance companies approve bilateral implants. Medicare does not.

Dawn Violetto introduced Child's Voice, an oral school for deaf and hard of hearing children. The school focuses on teaching the students to listen and speak. Parents who send their children to Child's Voice have opted to not teach them sign language. The school opened in 1986 with just a few students and it has grown to its present enrollment of 53 children. There are three sessions. In a home program, therapists see babies in their homes for early intervention. At 18 months the children enter the early intervention program at the school in the baby rooms. The main school begins at the age of 4 or 5 and some academics are integrated. The goal is to get the children into the mainstream classroom as fast as possible so they can learn with their hearing peers. Some students are ready for mainstreaming as early as age 4. Audiolgy began at the school last year. Some children were in the audience and Ms. Violetto said they would be available to talk. They make great progress each and every day. The later a child is implanted, the more difficult it is for him/her to pick up speech and language.

Andrea, a parent, introduced her daughter, Samantha. Samantha is 7-1/2 years old and is going into 2nd grade. She began at Child's Voice when she was 2 years old with a mild to moderate hearing loss and hearing aids on both sides. She has a condition called large vestibular aqueduct syndrome, a malformation of each cochlea which causes fluctuating hearing as well as progressive hearing loss. She is now profoundly deaf and received her bilateral implants after leaving Child's Voice. She received auditory therapy at home.

Next, Kevin and Kathy, parents, introduced Declan and Dylan, ages 2 and 5, who were born with severe to profound hearing loss. Dylan received his first CI when he was 8 months old and his second one later on. Declan was simultaneously implanted at 7 months. They both started in the toddler program at Child's Voice at 18 months. Both are doing very well.

Child's Voice is located in Wood Dale. It is nonprofit and many school districts pay for the children to attend. It is the only oral school in northern Illinois. Some children have moved to the area just to attend the school. You are welcome to visit and see the excellent teachers, bright, verbal children, and colorful surroundings.

To wrap up the meeting a representative from Choices For Parents introduced the "Guide by your Side" program. It is a support service to help and train parents who have children diagnosed with hearing loss. Information can be found on the group's website or else on the Illinois Hand and Voices website.

Technology Corner

By Ed O'Brien

Web CapTel from Sprint

Many of us have captioned telephones known as CapTel. CapTel is a desk phone and tethered to one or two phone lines. Some models can use the internet instead of a second phone line. They work great when we're at home. But another option from Sprint has been around for that works with any phone when you have access to a browser (Internet Explorer, Safari, or Firefox). You go to the web CapTel site and enter both the phone number where you are at and the phone number you want to call. You must register to use the service the first time, but the service is free. You can even keep commonly called contacts set up to enable quicker calling.

When might you use this? If you are at a friend's house, ask them if they have a phone near their internet PC or Mac. Then ask them not to pick up the next call since it will be for you. This is also helpful at work if your desk phone can be reached with a 10 digit number. Extensions can't be entered. If you have a cell phone, just walk to nearest internet terminal.

A new feature lets you login and wait for calls. When in this mode, you tell callers to call you at 800 933-7219. The 800 number will then ask them to enter your phone number. Your phone rings and your browser starts captioning the call. The site even has a tool to help you print little cards to print customized instructions for your friends and family.

If you use this feature and use it a lot, you might want to invest in a browser enabled phone like the iPhone or Q. These phones have built in browsers so you can get captions while speaking. This takes a little finesse and extra time to set up, but might be worth trying for some of us.

The name of this service? www.sprintcaptel.com

Listening With Liz

Fall is here and the annual Chicago Walk4Hearing is just around the corner. Excitement is building as we form our teams, make our pleas for support, and prepare to join hundreds of others who share the challenge of hearing loss.

The Walk has become a huge inspiration-fest. If you are fortunate enough to make the decision to join us, you are in for an incredible experience. On the day of the Walk you will be in the beautiful Lincoln Park area on the lakeshore. You will be surrounded by people of all ages who wear hats and t-shirts proclaiming their commitment to hearing.

There are babies in strollers, excited children running in all directions, teenagers who are becoming role-models, young adults, professional people, parents, older adults, a sea of humanity all devoted to this arena of hearing loss. All have experienced varying degrees of deafness in some way.

Many walkers are deaf or hard of hearing themselves. They are living lives that take a bit more work to get through each day. They will walk on October 18th, because their challenge has become their passion, a passion to raise awareness about hearing loss among the general public.

Some of the walkers are the wonderful professionals who devote their time to improving the lives of the hard of hearing community: doctors, nurses, audiologists, interpreters, CART personnel, hearing aid manufacturers, cochlear implant companies, teachers and others involved in education. We are so fortunate to have these people working to help make lives easier for the hearing impaired and supporting us in the Walk effort.

Some walkers are family members and friends of someone who is hard of hearing. They, too, live with the challenges of deafness on a daily basis. They are totally involved with this world of silence, adaptation, frustration, and loneliness. They understand why everyone needs to have some understanding of what it is like to face hearing loss 24/7.

We are aware how important it is to educate others and make our requirements known. We have experienced so many positive responses when we ask people to help meet our communication needs. But we know there is a long way to go. And that is why we Walk4Hearing so passionately. Together we shall help to educate and raise awareness for the millions of people who share the challenging world of the hard of hearing.

Show up for inspiration! Show up for exercise! Show up for socializing! Just show up!

Happy hearing. Liz

Editor's note: Please read "Listening with Liz", on front page of this newsletter, for more details about the Walk4Hearing

“Child’s Voice”

The article below was submitted to us by Child's Voice.

Child’s Voice is a non-public oral deaf school where children who are hard of hearing and profoundly deaf learn to listen and talk, without the use of sign language. Child's Voice, the only state-approved oral deaf education school in Northern Illinois, was founded by a group of dedicated and determined parents who believed that deaf children should have the opportunity to learn to talk.

The halls around Child’s Voice are never very quiet: sounds of children talking and making their way through the school fill every conceivable corner. Over the last month, however, the halls have been even more noisy than usual. On May 13th, Child’s Voice teacher Jeanette Hachmeister was named a 2009 Golden Apple Fellow and the school – filled with several reporters, school alumni, board members, children, staff and family – was transformed into celebration central as Jeanette accepted praise, speeches and even the proclamation of Jeanette Hachmeister Day.

The dedication that Jeanette embodies is evident throughout the school. The mission of Child’s Voice – to empower children who are deaf or hard of hearing to be successful in all educational and social settings by optimizing their listening, speaking and academic skills – is posted on the wall of every classroom. Founded in 1996 by a small group of determined parents, Child’s Voice gave an option to parents who wanted their child to hear and speak. At the time there was no auditory oral deaf education option offered in the Chicago area and families were forced to either relocate to another part of the country for their child to learn to listen and speak, or concede to the sign language programs that were offered locally.

Child’s Voice’s first graduating class consisted of one child in 1997 and this year, on May 29th, sixteen children graduated. These children will return to their local school districts, some entering kindergarten, others first or second grade, but all are prepared for success in a typical classroom with hearing peers. Of the eighty children at Child’s Voice, approximately half use cochlear implants to hear, the others utilizing hearing aides to amplify residual hearing. As the largest graduating class to date prepares to leave, some of the twenty infants and toddlers from the Early Intervention will transfer into the School Program to fill their seats.

As celebrations wrap up around the school and children prepare for summer school, it is clear that Child’s Voice has made a profound change in the lives of the families that have attended the school, some since their children were six months old. As parents shed tears while thanking teachers for giving their children the gifts of hearing and speech, the true magic is found amongst the children as they converse with one another, telling each other about summer plans and speaking up to be heard over all the chatter.

We would love to hear from you, in person at (630) 595-8200 or through our website, www.childsvoice.org.

News from Hearing Loss Association (HLAA)

The following articles were copied from HLAA's website, www.hearingloss.org

How is your television captioning doing these days?

Hearing Loss Association regularly receives emails from people complaining about television captioning. We've heard about delayed captions, captions that appear with letters dropping out, captions that are garbled or otherwise unreadable, and captions that are just plain full of errors. Captions that are not clear and easily read are not acceptable. The Federal Communications Commission (FCC) has oversight on broadcast, cable and satellite captioning, but they can't know what's going on unless we tell them. Make some noise! Inform your provider (your local broadcaster, cable or satellite company) about the problem first to give them a chance to fix it. If they do not solve the problem, be sure to let the FCC know. It's up to all of us to keep the pressure on. No one else will do it for us. For more information about filing a complaint with the FCC, visit <http://www.hearingloss.org/advocacy/telecomm.asp#filing>. And if you do send in complaints or concerns, feel free to send a copy to us: Advocacy@hearingloss.org Hearing Loss Association of America sits on the FCC's Consumer Advisory Council (CAC) and on the CAC's technical working group. We will take your concerns directly to the FCC to let them know that there are still many, many problems with captions that have yet to be resolved.

Coding of replacement parts for the external processor

On May 27, 2009, Brenda Battat, executive director of HLAA testified before the CMS Healthcare Common Procedure Coding System Work group on issues related to coding of replacement parts for the external processor of the cochlear implant. HLAA requested new codes for the most expensive parts, the sound processor and the cable/coil. Traditionally Medicare/Medicaid has categorized all replacement parts under a miscellaneous code that is below actual costs leaving the balance to be paid out of pocket by the patient. Brenda Battat spoke on behalf of HLAA members many of whom are implant users. She herself uses an implant. HLAA also submitted written comments to the workgroup.

HLAA Applauds United Healthcare's New Coverage of Bilateral Cochlear Implantation

HLAA is delighted to announce that at the urging of HLAA, United Healthcare, an innovative leader in the health and well-being industry, has reviewed appropriate scientific evidence and changed their clinical policies to allow coverage of bilateral cochlear implants for children and adults. This is good news for HLAA constituents as it provides medical care that can have a profound, positive impact on the quality of their lives. Bilateral implantation is increasingly sought by HLAA members because of the clear benefits of binaural hearing. Members have told us that the bilateral implant sounds more natural and provides them with greater speech understanding than when functioning with only one implanted ear.

In a letter to Stephen Hemsley, President and CEO of United Health Group, HLAA brought the lack of coverage for children and adults to United Healthcare's attention and requested that they take action to bring United Healthcare in line with other large insurers to cover bilateral implantation. At their July 2009 meeting, United Healthcare reviewed clinical evidence supporting the use of cochlear implants. Based on their review of evidence, they changed policy to cover bilateral implantation for children, and for bilateral implantation of adults with post-lingual hearing loss. Implementation of the expanded coverage will be in August 2009.

We applaud United Healthcare for making changes to policy that has the potential to positively impact the lives of many children and adults who need bilateral cochlear implantation.

CONTACT: Nancy Macklin, Director of Events and Marketing: nmacklin@hearingloss.org

News from the Board of Directors

We are pleased to announce that **Tina Childress** agreed to serve on ICIC's board. Tina is an audiologist, and a recipient of bilateral cochlear implants. She currently works as an educational audiologist in a public school, and is also the Cochlear Implant Outreach Specialist for the Illinois School for the Deaf. Tina has also worked as a Consumer Specialist for Advanced Bionics. Tina lives in the Champaign area with her husband and two daughters. --- Thanks Tina for joining the board. We look forward to working with you.

We were sorry to accept the resignation of **Irv Flangel** from our board. Irv had to resign due to heavy job commitments. We will miss Irv and his valuable input. We look forward to Irv's continued support and participation in ICIC activities. --- Thank you Irv, for your commitment and dedication to ICIC.

The ICIC board strives to increase awareness of hearing loss, and promote the benefits of cochlear implants (CIs). At our meetings we offer presentations by experts such as CI surgeons, audiologists and CI company representatives. We also reach out into the community to inform the public about the effects of hearing loss on individuals and their families, and about the availability of CIs and assistive hearing devices.

ICIC board members are: Liz Booth, Tina Childress, Terri Lambert, Ed O'Brien, Marc Siegel, and Hanna Benioff. We welcome input from our members. Please contact Hanna Benioff with your suggestions at benioff0@gmail.com; phone **630-964-1229**.

How Loud Is Too Loud? How Long Is Too Long?

Noise-induced hearing loss (NIHL) occurs when tiny sensory hair cells in our inner ears are damaged by noises that are too loud and that last for too long. But how loud is too loud, and how much time is too long? The answers are related: the louder the sound, the shorter the time before damage can occur. Read on to learn more about the mathematics of NIHL.

Why do decibel levels count?

Sound is measured in units called decibels. Decibel levels begin at zero, which is near total silence and the weakest sound our ears can hear. By comparison, a whisper is 30 decibels and a normal conversation is 60 decibels. An increase of 10 means that a sound is 10 times more intense, or powerful. To your ears, it sounds twice as loud. The sound of an ambulance siren at 120 decibels is about 1 trillion times more intense than the weakest sound our ears can hear. Sounds that reach 120 decibels are painful to our ears at close distances.

Scientists believe that, depending upon the type of noise, the pure force of vibrations from loud sounds can cause hearing loss. Recent studies also show that exposure to harmful noise levels triggers the formation of molecules inside the ear that contribute to hair cell damage and NIHL. These destructive molecules play an important role in hearing loss in children and adults who listen to loud noise for too long.

How does time multiply the danger of NIHL?

NIHL is related both to the decibel level of a sound and to the amount of time you are exposed to it. The distance you are from the sound also matters. A sound gets louder as you move closer to the source and softer as you move away from it. If you are far away from the sound, its intensity and its potential to cause damage are much lower. In addition, the impact of noise adds up over a lifetime. If you are exposed to loud sounds on a regular basis, your risk for permanent damage adds up as you age.

Source: National Institute of Deafness and other Communication Disorders (NIDCD).

Note: Hearing Loss Association of America (HLAA) is represented on NIDCD. Brenda Battat, executive director of HLAA was appointed as a new member of the Council. HLAA participation will ensure that research and issues important to people who have a hearing loss will be considered.

This & That

Medical Alert Bracelets

In case of accidents, some cochlear implant recipients have decided to wear medical alert bracelets to inform medical personnel of their implants. There is no specific recommendation for the information that should appear on the bracelet. However, it is important that people are aware you have a cochlear implant and that you cannot have an MRI. Other information could include your cochlear implant manufacturer's phone number and that you are deaf so that medical personnel will know you may not be able to hear them.

Disposal of used batteries

Non rechargeable batteries include alkaline, zinc-air, and silver-oxide. Most cochlear implant 675 high power batteries are the zinc-air. Rechargeable batteries can include Nickel-Cadmium NiCd, Metal Anhydride, and Lithium ion. These would include the rechargeable batteries used in Advanced Bionics CIs as well as the rechargeable AA batteries used in the body worn Cochlear Corporation and MedEl devices. Advanced Bionics' batteries can be returned to the company for recycling. Or, you can take them to a local drop-off site in your area. Also, stores such as Home Depot, Wal-Mart, and Best Buy will accept used rechargeable batteries for recycling.

This newsletter and past newsletters can be found on our website

www.illinoisci.com

ICIC newsletter

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