Hearing Loss Association of America
Illinois Cochlear Implant Chapter

February 2011

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A Happy 2011 to All!

By Hanna Benioff

2011 promises to be a good year for ICIC. Our board scheduled interesting meetings with excellent speakers. The year started with a most informative presentation by Pam Fiebig, audiologist, about *"Effective Communications between CI Users and the Audiologist".* Future presentations this year include: *"Aural Rehabilitation for CI Users"* with Lynn Wood, audiologist, *"Ask the Doctor",* an extended question and answer session, with Dr. Michael J. Shinners, *"21st Century Captioning Act"* with Lise Hamlin, Director of Public Policy, Hearing Loss Association of America (HLAA). We are thankful to Lise for making this special trip from Washington D.C., *"Safety Issues for the HOH"* presented by our own members. Tina Childress and Ed O'Brien, and *"He Said, She Said" – Challenges and Practical Solutions for D/HH and hearing couples"* with Tina and Matt Childress.

As we start a new year I want to offer thanks to the many dedicated people who support ICIC and who make it possible for us to meet and share experiences and information:

Inside This Issue

A BIG *Thank You!* to our speakers who volunteer their time to educate and share their expertise.

A *Thank You!* to our members who come to meetings not only to acquire new information but also to share their experiences and offer support to each other and to persons who are contemplating a cochlear implant.

And, a special *Thank You!* to our board members for their time and efforts to promote ICIC and increase awareness of hearing loss and cochlear implants to the population at large.

Best wishes for a good new year and the best of hearing! We look forward to seeing you at our meetings.

Hanna

Next ICIC Meeting

When March 19, 2011
2:30 – 4:30 pm

Where Morton Grove Park District
Prairie View Center
6834 Dempster Street

Getting a Cochlear Implant has a few steps. First you have the surgery. Then you map and re-map to optimize your sound experience. This meeting discusses a third and often overlooked step – Aural Rehabilitation.

Presentations

Aural Rehabilitation for CI Users

By Lynn A. Wood, Audiologist

Mini-Tech Topic

Live captioning provided by CaptionFirst

New Advances in Cochlear Implant Technology

- **Dr. Richard Wiet**
  Ear Institute of Chicago
  (A recap by Liz Booth
  Of ICIC November Meeting)

Dr. Wiet talked a little bit about the history of cochlear implant technology beginning with two Frenchmen who experimented about 53 years ago. They probed through their eardrum and heard a blast, but it did not work out very well. In 1972, the first single-channel implant was developed by William House and the 3M Company. It eventually was FDA approved and Dr. Wiet was one of 12 physicians to begin cochlear implants in the U.S. He did the first Illinois implant in 1981. He was a bit disappointed with the results after implanting 8 people and discontinued the surgery. In 1984, he saw that patients with multi-channel implants heard a lot better. He has been in the CI field for 25 years now and his practice has expanded to four physicians and five audiologists.

Dr. Wiet explained that our cochlea is tonotopic with high frequencies at the first bend and low frequencies at the apex. With hearing loss, we've lost our hair cells, mini transmitters of sound, in the cochlear and that gap must be crossed. In the early implants, there was quite a bit of damage, but the new implants are softer with new technology to get better sound transferred to the center core of the cochlea. These designs allow for more gentle insertion.

"Dr. Wiet has been in the CI field for 25 years"

There are improved electrode arrays and surgical techniques and all the companies have concentrated on attempting to preserve residual hearing. The idea of losing residual hearing is often difficult for a patient to accept. Increasingly patients are asking for two implants at once, however most people prefer sequential implantation.

Today's circuit boards are about the size of a quarter and the internal implants are much thinner by 40%. They are smaller with a shorter surgical length that is implanted. There are removable magnets. The improved internal implants have paved the way for expanded candidacy criteria. In the "80's, you had to be profoundly deaf, stone deaf. Today it is from profound to severe to moderate-severe. The discrimination level used to be close to zero and now it is 40-60 percent word recognition score.

Dr. Wiet's practice deals with all three CI manufacturers. He shared that when he started out, there were eight companies, but five have dropped out. Cochlear Corporation was FDA approved in 1984; Advanced Bionics was approved in 1995; and Med-El was approved in 2001. Over time, the newer implants were developed to hug the modiolus, the center core of the cochlea, so the reception is better. A split array was developed to allow insertion into cochlea compromised by disease.

Patients often ask Dr. Wiet his opinion of the three companies. His answer is that 80% of patients will get an open set discrimination which means they will hear and understand without lip cues. There are others that don't perform as well. There are some things that impact the outcome such as duration of deafness, motivation, family support, etc.

Sound Processor Overview

- **Kathy Highhouse,** Audiologist
  (A recap by Liz Booth
  Of ICIC November Meeting)

Kathy Highhouse continued the presentation with a history of sound processors. In 1967 the initial soundboards were very large and the patient had to go into the doctor's office in order to hear with the early single-channel implants. Just five years later the first wearable processor was developed.

Cochlear Americas: Most first generations with the 22 channels started with the Spectra. Many have now been upgraded to the Freedom. The first behind-the-ear processor was in 2001, the Sprint. Today there is the N5 which is thinner and has advanced technology. It has a remote control system which enables users to adjust programs and volume easily and a feature called auto phone which connects the phone to the T-coil. There is also "zoom" which helps in noisy situations. There is improved dual microphone technology to help in background noise. It is water resistant. If you have a Freedom implant, you can upgrade to the N5 processor. Sometime in 2011 it will be available for the N24 users. It will not be available for the N22 users for about 3-4 years. If you are using an N5 you should see your audiologist for updates to the remote.

Advanced Bionics: Initially there was the body-worn processor followed by the behind-the-ear model. It was the first implant company to offer rechargeable batteries. The newest processor is called the Harmony which has the ability to use a speech strategy called Hi Res Fidelity 120. It offers better sound quality overall which people have described as more rich and full, similar to going from seeing in black and white to seeing in color. It has helped with speech as well as music. There is a feature called autosound which automatically adjusts to various listening situations. The T-mic is a significant feature of the Harmony originally which eases phone usage and improves overall listening. There is an integrated T-coil. The Harmony processor is now available for upgrade for all generations of Advanced Bionics implants. There is a new coding strategy called clear voice under FDA trial which will offer better hearing in noise. AB has a new relationship with Phonak, a hearing aid company. This will lead to smaller processors and Bluetooth technology.

Med-El: This Company's history started overseas, but they were FDA approved in the U.S. in 2001. They had the first behind-the-ear processor in 1991. The current sound processor is called the Opus 1 and 2 with some options. The Opus 2 is very thin and comfortable. A remote control is used to fine tune it. It has auto sound and a T-coil. The Opus 2 can be upgraded for the Combi internal implant recipients. There are new features coming in 2011.

The hybrid cochlear implant is a merger between electrical stimulation through the cochlear and acoustical stimulation through normal sound conduction. This will preserve low frequency hearing and only help with hearing in the high frequencies. Candidates would have good low frequency hearing, but profound high frequency loss. It is under FDA trial through Med-El and Cochlear. The Ear Institute of Chicago is participating in this trial.

Looking to the future, everything will get smaller. Research is being done on a fully implantable cochlear implant, but there are a lot of things to work out with the microphone, batteries, sound quality, etc. It probably will not be available for many, many years.

History of HLAA

- **Dick Meyer**
  Past HLAA President
  (A recap by Liz Booth
  Of ICIC September Meeting)

Mr. Meyer's hearing loss is genetic and it runs in his family. His uncle was Rocky Stone who founded SHHH (now known as HLAA, the Hearing Loss Association of America).

Hearing loss is an invisible disability. No one knows we have any problems at all. HLAA has formulated some ultimate goals: hearing loss needs to be recognized as a health issue; hearing aids and cochlear implants need to be recognized as a standard of care; hearing loss needs to be de-stigmatized in society; there needs to be protection of the consumer and this will be achieved through education.

In March of 2010, HLAA revisited the goals and added the following: reach out to the public, parents, young adults, and hearing health professionals; increase technology awareness; partner with corporations and organizations that share HLAA values and goals; and strengthen our online presence through the HLAA website.
Prior to 2004, there was a Cochlear Implant Association. When that was forced to close, HLAA absorbed many of the members and chapters of that organization. HLAA has been trying to meet the needs of its CI membership which stands at about 25%. 2% are bilateral, and 29% are HLAA convention attendees. Through specifically designed programs HLAA tries to meet its members' needs.

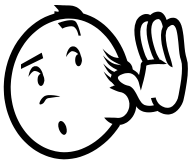
There are CI workshops and research symposiums at the annual conventions and articles that deal with CI appear in the magazine, *Hearing Loss*. There are sections on the HLAA website devoted to cochlear implant as well. HLAA hosts a chat room on CI each week and Webinars are also presented. CI manufacturers exhibit at the conventions and sponsor events.
Dick pointed out that HLAA does active lobbying in Washington, D.C. They have been successful in getting Aetna to change its policy to cover bilateral implants. Work is ongoing to ensure adequate Medicare and Medicaid reimbursement for CI procedures to hospital CI clinics. HLAA also works with many individuals on CI insurance coverage disputes.

The former name of HLAA was Self-Help for the Hard of Hearing or SHHH. At that time it was a proper and good name. However, the environment has been changing with new technology and the hard of hearing are no longer just associated with hearing aids. HLAA seeks to be an inclusive organization and so the name was changed to reflect the broad membership.

HLAA's expected outcomes for consumers include access to low cost, easy-to-use, hearing aid-compatible assistive listening systems, increased hearing and access in public venues and home environments, and double the functionalities of hearing aids by using them as customized loudspeakers. The expected outcomes for audiologists and hearing aid specialists include greater consumer satisfaction with hearing aids, more client referrals, greater understanding of loop, telecoil, and other assistive listening technologies, fewer hearing aids returned, and participation in promoting compliance with ADA requirements.

HLAA's national impact can be seen as the organization was able to reverse DOJ's employment testing policy and stop sales tax on hearing aids. The FCC broadband plan includes HLAA's recommendations for accessibility and the ADA can require captioned movies. In the area of employment HLAA met with EEOC to revise

guidelines, presented a job qualification testing position paper, is researching Federal agency hiring and testing policies, and has an employment tool kit online. In the consumer protection arena HLAA specifies what to expect when being fitted and purchasing a hearing aid, helps with state regulations regarding the sales of hearing aids and dispensing laws, and is a partnership in "giving consumers a voice in advancing standards of hearing health care."



Listening with Liz

- Liz Booth

How did you know about that? Where did you get that idea? When did we discuss those things? The kids said what? Who were they referring to? Why don't I know these things?

Incidental information……..it's a big part of daily life, but a part that those of us with hearing loss consistently miss. Conversations occur at the table next to us at a restaurant. The kids talk with their friends in the backseat of the van. There are announcements over the PA system in the stores. People talk in front of us or behind us in a bus, airplane, or train. Radio and TV blare in the background.

Later, when others refer to information gleaned in these situations, we have no idea where it came from. It doesn't matter that we, too, were eating in the restaurant, shopping in the store, riding in the van, bus, train, or plane. We, too, were present when the TV and radio were on. But because we can focus on just one auditory thing at a time, we are often out of the informational loop.

Four of us recently took a trip to Seattle and Vancouver. It didn't take me long to realize that I was missing some very interesting facts and conversations. Shortly afterwards, I had the opportunity to discuss this frustration with a hearing loss researcher. Focus seems to be the problem.

People with normal hearing can choose to focus on more than just the primary conversation. Background information can be processed by the brain if it is heard and accessible. But those of us who struggle to hear must focus on the situation at hand. We must give all of our energy to the person addressing us. We are using all the cues available: limited sound, lip-reading, body language awareness etc. We are focused on doing everything possible to comprehend the conversation. If other things happen around us, we cannot be aware of them because we would lose our focus. Thus, the incidental information is lost to us.

Add that to the fact that often we simply cannot hear some of the things going on around us, and that void is inevitable and complete.

What can we do about this? Sometimes we can pick up this incidental information in focused conversation after the fact. Sometimes we can ask someone to clue us in when we realize that we have, indeed, missed something we'd like to know. Sometimes we'll not know that we've missed anything and are none the worse off for it. Frustrating? Disheartening? Sure. But perhaps we can hold onto that well-known prayer written by Reinhold Niebuhr in the 1930's or 1940's: "Grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference."

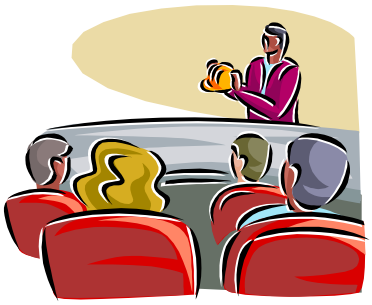
I wish you serenity and acceptance in your daily hearing life.

Chapter News

HLAA National Convention
Washington, DC
June 16 -19, 2011
www.hearingloss.org/convention

This year's convention will be held in Washington, DC at the Hyatt Regency Crystal City. This is a great city and a nice hotel. If you haven't attended an HLAA convention before, you should. 29% of the attendees have a CI.

This year, HLAA has arranged for a captioned version of play "Wicked" on the 17th.



Remaining 2011 Meeting Topics

March 19, 2:30pm
Aural Rehabilitation for CI Users and Audiologists
Lynn A. Wood, Audiologist

May 21, 2:00pm
Ask the Doctor – a brief CI topic followed by a Q&A session.
Dr. Michael J. Shinners, MD Otolaryngology

July 16, 2:30pm
21st Century Captioning Act
Lise Hamlin, Hearing Loss of America (HLAA)

September 17, 2:00pm
Safety Issues for the Hard of Hearing
Tina Childress and Ed O'Brien

November 19, 2:30pm
He Said, She Said – Challenges and practical solutions for deaf and HOH couples
Tina Childress, Audiologist, CI recipient
Matt Childress, Tina's husband

Meetings at 2:00pm are in Glen Ellyn
Meetings at 2:30pm are in Morton Grove

Visit www.illinoisCI.com for more information

Ed O'Brien's Story

- Ed O'Brien, ICIC Board

I'm a first born baby boomer with four brothers and a sister. Language was an important part of growing up. That was probably because both of my parents were English majors. No one had any disabilities and no one I played with did either. One Christmas, I came down with a high fever at my grandmother's house. All I remember was waking up three days later in the hospital with my parents and a doctor in the room.

I had come down with Meningitis and had been given an experimental drug. The drug worked, but the high fever wrecked havoc to ears. One ear was deaf and the other had a moderate loss. At the time, I didn't notice and no one told me. Everyone would talk more loudly in my good ear. I didn't pick up on that behavioral change.

Back then, giving children hearing aids was a new concept. I was in Kindergarten at the time. The normal path was to treat it as a learning disability. Luckily for me, my parents sent me to Northwestern University Audiology research department where I underwent countless hearing tests for several months, the culmination of which was a recommendation I get a hearing aid. I loved my new toy. I felt so lucky to have this nifty piece of electronics that had a volume control. I proudly showed it to my friends and probably even made a few jealous.

I never missed a beat and I never thought I was hard of hearing. My friends didn't see me that way either. I was always the geek. My favorite toys were usually auditory in nature. Nothing was more exciting than my first tape recorder. Whenever it was time to get a new hearing aid, I would be on cloud nine for weeks before and after the upgrade.

I went to the University of Illinois at Champaign and majored in Mathematics and Computer Science. I found computers even more exciting then hearing aids. After college my career pushed me into computers and programming them. I did well and would buy a new hearing aid every couple of years. When the digital models came out, I could not resist them.

As I started my 40s, I began to realize I wasn't hearing as well I used to. My audiologist noticed slight drops each time I was fitted for a new aid. Thinking back, the real problem was my speech perception was slipping. My reaction was to make speech louder and louder. As time went on, I started to slowly withdraw and did a lot of bluffing. My audiologist still loved me. I would buy anything she had to offer. She never mentioned a CI. I learned about them on my own. (I'm very grateful to Al Gore for inventing the internet.) When I was 48, I went to an ENT who referred me to a CI Surgeon, who said I heard too well for a CI.

A year went by and I went to see a different surgeon, Dr. Dennis Moore. He said I was very close to being a CI candidate and suggested I come back in two months. At this point, my speech comprehension was about 60%. To me, I might as well risk losing it all as I could not communicate. I avoided going out. I was officially hard of hearing for the first time. When I took my next hearing test I didn't try very hard. This was the first test I did not want to pass! Dr. Moore said I was a candidate and suggested I go home and give it some thought. Forget that. Just tell me the next available surgery date. We set it for two weeks later. We decided on doing my good ear because it was expected to have the best results.

The surgery was uneventful and I was turned on six weeks later. My new CI audiologist and I were both surprised how quickly I took to it. I even made a phone call before leaving my first mapping. I went in with the low expectations and high hopes. Within a few weeks everything sounded just like I was used to. (Please note, this is not a typical outcome.)

A couple of weeks ago, I had my quiet ear implanted. It will be turned on soon and I'll be able to finish this story. Questions?
EdMutare@gmail.com

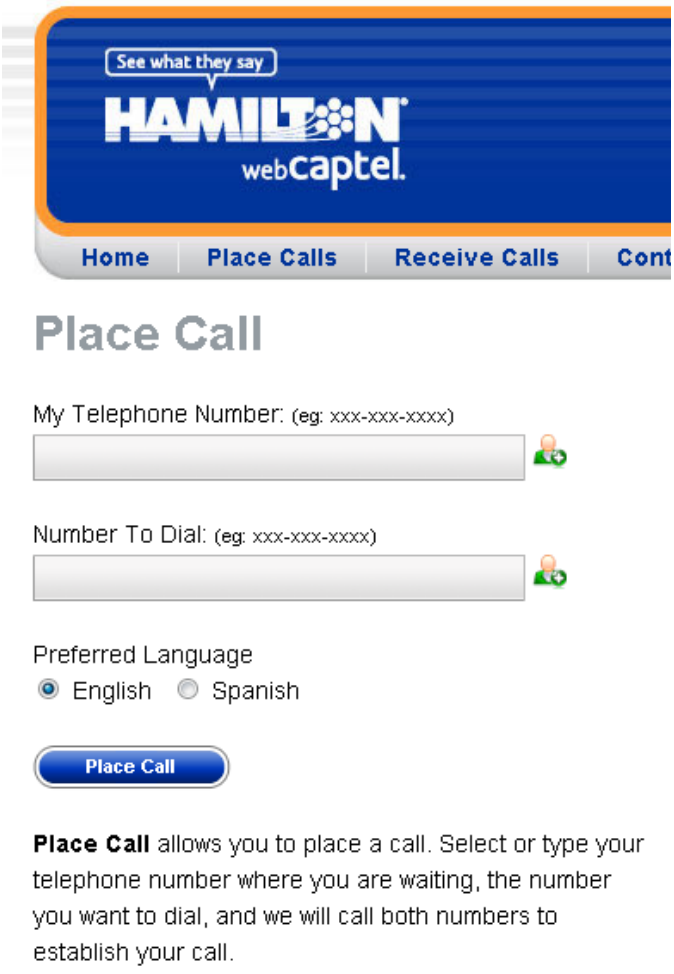
Tech Corner

- Ed O'Brien, ICIC Board

CapTel on the Web – Free!

If you find yourself somewhere with ANY phone and an internet browser, you can make a captioned call for free. Next time you want to make a call at your friend's house, ask if they can bring up a browser and visit www.hamiltonwebcaptel.com or www.SprintCapTel.com. Both sites provide the same service and both are free.

The first time you use this service you will need to select **Register** to set up a username and password.



After that you just login, select **Place Calls**.

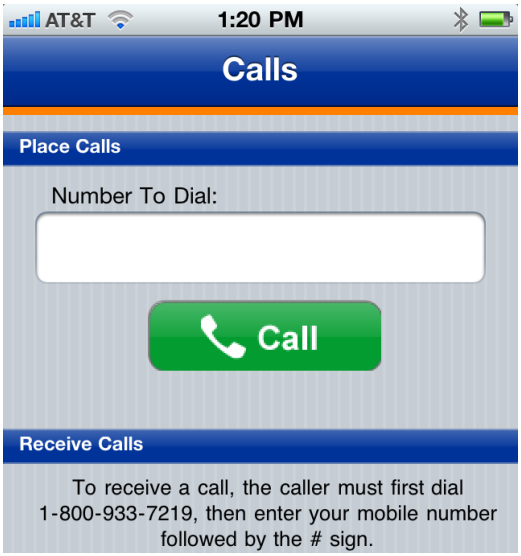
Enter the phone number of the phone you'll be talking on. Then enter the number of the person you wish to call. Enter the phone numbers starting with the area code. Don't include a leading 1. The service is only for USA calls.

Finally, press **Call**. A few seconds later, Captel will call your phone. And then conference in the person you want to call.

A new screen automatically appears with CapTel captions – just as if you had used a CapTel phone to make the call.

Hamilton's Web CapTel is also available as an application for iPhone and Android smartphones. If you have a Blackberry phone, Sprint has a mobile version of their website.

The Hamilton application is slick. You don't have to keep entering your phone number or password. There is a catch. You can't read the captions on your smartphone if you're holding the phone up to your ear. So be sure to use the speakerphone, or loop or Bluetooth.



Did You Know?

Not all batteries are the same

If you use disposable batteries in your implant you should know batteries have something called a capacity and a discharge rate. The circuits in a cochlear implant need a high discharge rate in order to stimulate the implant properly. How much and how fast energy is pulled varies by processor and speech strategy – and of course how loud it is.

Your rechargeable battery packs have great discharge rates, but for many of us they do not last as long as disposables. That's because they have less capacity.

So when you shop for batteries, be sure to look for ones designed for cochlear implants. They will be labeled with phrases like high drain and high discharge. Using lesser batteries often makes it seem quieter than normal.

Coming in March

Put 2:30pm, March 19 on your calendar!

Lynn A. Wood will give a presentation on:

"Aural Rehabilitation for CI Users"

After the surgery and few mappings, what next? Come to the meeting and find out.

The meeting will be held at the Morton Grove Park District Prairie View Center.

Cool Websites

TecEar

www.TecEar.com

This web site is for an online store dedicated to the distribution and education of the latest Hearing Assisted Technology (HAT). Unlike a catalog format, this site is extremely educational and unbiased. The owner spends a great deal of time updating his site. He even provides great matrix reviews showing different brands of an item and their features. It is the first place I go both for answers and for any purchases. Learn about Bluetooth, Loops and FM systems here.

CC CAPTIONFISH:MOVIES

www.CaptionFish.com

Believe it or not, there really are captioned movies at public theaters. The problem is not all movies and showings are captioned. How do you find those that are? Visit this web site. Spend some quality time there. You enter a zip code or city and voila! – up comes a list of movies and show times.

Do you have a cool web-site to share?
Tell me about it at:

edmutare@gmail.com

Hearing Loss Association of America
Illinois Cochlear Implant Chapter (ICIC)

We're on the Web!

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