



## *Illinois Cochlear Implant Chapter (ICIC)*

# ICIC newsletter

January 2009  
Illinois Cochlear Implant Chapter  
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### *Listening With Liz*

The holidays are behind us and I'm exhausted. Do you feel the same way? There were so many extra things to do and events to attend during the month of December: shopping, wrapping, decorating, baking, writing, hosting, worship services, family gatherings, neighborhood parties, office parties, travel, etc. Or maybe you didn't have too many things to do, but simply got tired of all the typical holiday hoopla. Whew! No wonder exhaustion sets in with the new year.

But we who live with the challenge of hearing loss do not just deal with the physical exhaustion. Not hearing well adds to our level of exhaustion, mentally and emotionally. No matter what we are doing, we are constantly anticipating, strategizing, straining, and stressing. Will I be able to hear the salesperson? Will I be able to follow the conversation around the table? Will I be able to understand with the music in the background? Will I be able to greet others after worship? Will I be able to telephone holiday greetings? Will I be able to manage the noise in the environment?

No wonder exhaustion sets in! We all have learned some strategies to use in so many of these situations. We all try very hard to actually use these strategies to make things easier on us and those around us. But as the stress increases and our frustration deepens, sometimes our best intentions are lost in the moment and we might suffer a "meltdown," or withdraw, or become angry or depressed. It is certainly exhausting.

So now December is past and we need to regroup and reenergize. We had some really good times and that is what we need to focus on. There were also not-so-good times because we could not hear and participate fully. However, we know that is part of our reality and, to use some modern-day jargon, "it is what it is." We need to think about the beauty and love we experienced, the good conversations we had, the people we touched by being there for them, the peace we experienced. We need to take a deep breath, stretch, and smile at the good memories as we settle back into our regular routines.

Happy hearing. Happy New Year.

*Liz Booth*

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### **What is ICIC?**

**Illinois Cochlear Implant Chapter (ICIC)**, a member of the Hearing Loss Association of America (HLAA), is an organization for cochlear implant recipients, prospective recipients, professionals, and other interested parties. ICIC offers support and practical help to current and prospective Cochlear Implant (CI) users, as well as information about CIs through presentations by experts including surgeons, audiologists, and CI manufacturers. Annual donations are \$25.00

***DISCLAIMER:** The Illinois Cochlear Implant Chapter (ICIC) neither recommends nor endorses products, people or services. Opinions expressed are those of the individuals, not those of ICIC.*

## Minutes of ICIC Meeting

November 15, 2008

Edited by Liz Booth

### Presentations by representatives of: Advanced Bionics (Kerry Roesch), Cochlear Americas (Jessica Melton and Kara Murphy), MedEl (Pam McGuinty) and FCC representative Chris Jelinek, on The Digital Television Transition

Kerry Roesch is an audiologist who works with Advanced Bionics (AB).

The AB speech processor is called the Harmony. The job of the speech (sound) processor is to gather information, acoustic sound from the environment, and convert it into an electrical signal that the device can recognize. The Harmony is unique and offers some different features.

One of the components of the processor is called auto sound. It is an opportunity for the processor to capture a large window of sound. There is an automatic gain control which is a technology that some hearing aids use as well. That combination is a way that sound is preserved in a very natural state when it is being converted to be used through an

implant. The t-mic and the new speech coding strategy called HiRes 120 are two more new things within the Advanced Bionics systems.

Auto sound delivers a wide input dynamic range. The natural ear has the ability to collect 100 to 120 decibels of sound, so the goal is to maximize how much sound can be delivered through the sound processor. There is also a feature that automatically controls the gain of the system so you do not get over stimulated or things become too loud too fast.

In a narrow range of hearing, there is a small window to listen to sound, so soft sounds can be omitted from the signal and loud sounds can be switched or compressed. If that is happening in a very narrow window, there can be distortion in how the sound processor processes the information. With a wider input dynamic range, there are less sounds being omitted and fewer sounds being compressed. The integrity or the naturalness of the acoustic signal is kept. Patients who listen with this wide dynamic range in addition to the automatic gain control prefer the way music sounds. They do better when listening in quiet, and better listening in noise. That is an advantage of this different technology.

With this technology, patients' hearing in the real world can be improved. When you go from one environment to another, the system adapts for you. The automatic sound processing allows the system to get quieter or louder without the user having to manually make the changes.

The other feature that is unique to the AB sound processor is the t-mic. This microphone sits very naturally just outside the ear canal. When a CI user picks up the telephone they can listen in a very natural manner without holding the phone up high to the headpiece or a microphone on top of the processor. With a t-mic in that position, patients do better listening in noise, in quiet, and appreciating music. It is both a sound enhancement and a convenience. It also allows the wearer to connect to things such as Bluetooth, earphones, or an I-Pod very easily without having to use a patch cable. .

The third component of the Harmony system is the coding strategy called HiRes 120 or Fidelity 120. Information is presented in much broader spectral bands. The electrodes in the cochlea discharge energy and sound is coming in. It gets discharged into a band or range. When you have another pitch coming in, another sound, but it is very close to the first pitch, they will be discharged into the same channel or the same frequency spectrum. What AB has done is broaden the number of spectral channels. By adding more channels in between the electrodes, better pitch perception results. This has been a huge benefit for patients.

This coding strategy is able to be used on patients who were implanted even back in 2001. A large number of CI users who used the older conventional sort of strategies with fewer spectral bands of information were changed to the newer coding strategy. They also received the two other updates. Universally, patients preferred the newer strategy. This new system works with any AB internal system implanted since 2001.

The internal device now being used is the HiRes 90K. It has the capacity to upgrade to the newest speech coding strategies. The access to auto sound, the t-mic, and the 120 spectral band can be applied right now, but researchers are constantly looking at new ways to stimulate through the system with the intention of maximizing how the acoustic sound will come across to patients. Patients who transition from a traditional coding strategy to HiRes and HiRes 120 say listening to music is so much better. It makes sense that having more bands allows for more appreciation.

The goal of Advanced Bionics is to provide the best technology available. They also emphasize customer service and offer the support that CI users need. The Bionic Ear Association is a very strong organization for customer support and education. There are people who can talk to you about their own experiences.

The Listening Room is a free service to you. It is an on-line community developed by Advanced Bionics, available to anyone. The first phase was for children and offered techniques that children could use to learn how to listen with their implant. There is now an adult site in the Listening Room. There are techniques and strategies that you can use at home on your own. You can print out the activities and do them on your computer. You can even download them to an MP3 player and do them on the go. An auditory therapist and people from AB developed the site. Go to [www.hearingjourney.com](http://www.hearingjourney.com) to access the Listening Room.

Jessica Melton is an audiologist with Cochlear Americas. The Freedom cochlear implant system has the contour advanced internal device and different wearing options of the outer processor. It can be worn on the ear itself, in a body-worn configuration, or in a baby-worn configuration which is for adults as well. No matter how you wear the device, the sound quality is always the same. The snug fit is new and is nice to use if you have trouble with retention or keeping the device on the ear. There is an accessory socket at the bottom of the controller where you can plug in a number of different accessories, whether it be an audio input cable for a personal stereo system, computer, or TV.

In comparing the new Freedom with the previous device, the Contour, patients enjoy the new technology and are performing better. Patients improve over time, even up to a year.

Smart Sound 2 is a new system that helps to make the sound in the environment natural. This sound processing takes place at the front end and seeks clean, clear sound before it gets to the internal device. Under the umbrella of Smart Sound come whisper, ADRO, ASC and Beam.

These can be adjusted for different environments based on what you are listening to, whether it is in quiet, noise, or music. In Smart Sound Two, ADRO has been combined with auto sensitivity. Now the programs are referred to as your everyday program, your noise program, your music program and your focus program. Patients like the combinations. ADRO plus auto sensitivity is a popular one, especially in noise. If you have not been to your audiologist recently and are not familiar with Smart sound Two, it would be good to ask about these options and try them yourself.

There is also an option with the T-coil always on. Your audiologist can program this into your device.

If you upgrade to the Freedom from the Spectra 22 sound processor, the sound will be very different and you'll be hearing a lot more. This upgrade is possible using your original internal device so no more surgery.

Kara Murphy continued presentation. She is the Awareness Manager of Cochlear Americas. Her daughter, Eve Murphy, has a cochlear implant and wears a hearing aid in the other ear. She is bimodal.

Kara addressed the concept of bilateral cochlear implants. People who have bilateral implants say they feel more confident and connected and have more comfort. They are able to localize sound better. They do better in a variety of environments: quiet, noise, and reverberation (echo).

Cochlear has a variety of tools and resources available. There is the on-line troubleshooting tool, the new Phone-with-confidence, support services, and free insurance support called OMS. There is also an on-line store. The troubleshooting tool is used via the internet through the Cochlear Americas website. To address a problem you would go through steps and options on the website. Phone-with-confidence was developed by a Cochlear employee, Scott Reinhart. He has bilateral implants. This is a tool to use when you are trying to learn how to listen on the telephone. You can call

1-800-458-4999 and listen to either a female voice or a male voice. You can listen to a passage or a list of words. It changes every day. You can go online and read along.

The Cochlear Awareness Network is a public awareness network of recipients who have either a cochlear implant or a Baha implant. They communicate with candidates and support them through the process, helping them through the journey towards a CI. These are volunteers who are connected with candidates who have something in common. Some are parents of children with CIs. The Cochlear Community is similar to Facebook, but more private. It is on-line communication and can be accessed along with Phone-with-confidence at [HYPERLINK "http://www.cochlear.community.com"](http://www.cochlear.community.com) www.cochlear.community.com. There are also tools for parents to use. There is a Cochlear celebration coming up in March in Anaheim, CA.

Pamela McGuinty is a representative from MedEl and has bilateral cochlear implants. She has the older generation technology in one ear and the brand-new generation in the other ear. This is the 7th generation of implants from MedEl, a privately owned company that puts 34% of profits back into research and development.

The latest system is called the Maestro system. The patient can choose the external processor, the Tempo or the Opus 1, and the internal processor, either the Pulsar or the Sonata. There is no difference in the technology, just in the shapes. The surgeon helps you decide if there is a reason

The latest system is called the Maestro system. The patient can choose the external processor, the Tempo or the Opus 1, and the internal processor, either the Pulsar or the Sonata. There is no difference in the technology, just in the shapes. The surgeon helps you decide if there is a reason to go with one or the other. It is designed to help the audiologist figure out how to get the most information from your implant. There are different electrodes for different types of classification for something in your ear.

MedEl has the deepest electrode insertion. They try to provide the most information and the most natural sound. Comparing this to piano keys, they are trying to give you the entire piano keyboard, not just part of it.

The external speech processors, the Tempo and Opus 1, can either have switches on top or else be controlled by a remote. They both have automatic gain control and the iris recognition system so you don't put the implant on the wrong side. The Opus 2 has special features the Opus 1 doesn't have. It has the integrated telecoil where you do not need a separate telecoil program. You can also do microphone together or just microphone. There is a private alert that beeps when the batteries are going to die. There is a fine tuner that will work with bilateral implants. The program can be locked so it cannot be inadvertently changed.

Your speech processor can be ordered in six different colors. Batteries last 3-5 days when using #675 batteries. There are modular wearing options with a rechargeable battery pack with batteries lasting 10-12 hours. The baby BTE can be worn on the shoulder for children and is also good for active adults. The Opus 2 has an FM extension which can be used with FM systems and Bluetooth and an MP3 player.

The Opus 1 and the Opus 2 have a fine structure processor. This provides more information to people for enjoyment of music. 91% of people like it more with this fine structure processing. The two different methods are sampling systems and virtual sounds that give more pitch information.

MedEl has outstanding customer service. They are available 24 hours a day, 7 days a week. There is a reimbursement support specialist group also. Reliability information is provided on the website as well as product information, and peer support.

The program continued with Chris Jelinek from the Federal Communications Commission who spoke about the upcoming transition to digital television. This will take place on February 17, 2009, and will be the biggest change since color was introduced back in 1950. The change will not affect people who have cable or digital television. It will only affect those people who are using outside antennas or rabbit ears.

As technology gets better, we have to change along with it. Congress mandated that this be done because they want to take some of that scarce radio frequency that the analog TVs are on now and use it for public safety. Those frequencies are going to be reassigned for voice, fire, ambulances, school buses, etc.

The advantage of digital is that you use much less of the frequency spectrum. We can put a lot more intelligence or information in a very small portion of the frequency range.

Digital is also going to offer a better picture and better sound. It is interference free. Also they are going to do multi-casting, a lot more programming in a small amount of frequency. The same channel can have as many as four different programs transmitted at the same time. The TV stations can choose what they want to do with it.

In order to ready for the February transition, you have to have one of three things: a digital television, cable, a satellite or subscription TV system, or a converter box. The converter box is a digital to analog converter box. You can still continue to use your analog television as long as you have the converter box attached to the TV. The government is offering two coupons, two \$40 coupons to be put towards the price of the converter box which cost between \$50 and \$75. You can get a coupon by completing an application. Call in for one or get it on-line. Once ordered, it will take 1-6 weeks to get the coupon which look like a charge cards. It is only good for 90 days. Prices vary on the converter boxes so shop around. They all have to have remote control, have the connection wires attached, and allow closed captioning. The box is very simple to connect. You take the wire from the antenna and place it into the box. The wire that comes with the box is attached to the back and that goes into the back where your antenna wire went.

Act now and be prepared for the transition on February 17, 2009.

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## **DID YOU KNOW?**

### All That Noise Is Damaging Children's Hearing

The Children's Hearing Institute reports that hearing loss among children and young adults is rising in the United States, and that one-third of the damage is caused by noise.

According to the American Academy of Audiology, about one child in eight has noise-induced hearing loss. That means some five million children have an entirely preventable disability that will stay with them for life.

The academy has begun a "turn it to the left" (the volume dial, that is) awareness campaign in hopes of protecting current and future generations of youngsters from unwittingly damaging their hearing. Often, the problem is not detected until children develop persistent ringing in the ears or begin to have learning or behavior problems in school because of trouble understanding speech.

Although newborns are now routinely screened for hearing loss, there is no federal mandate for screening the hearing of school-age children. What testing is done often fails to check hearing at high enough pitches, a federal research team pointed out in the journal *Pediatrics*.

If a significant hearing problem is diagnosed, even if just in one ear, a hearing aid can make a world of difference. Currently, only 12 percent of American children with significant hearing loss use an aid that can help them hear properly. The high cost of hearing aids and lack of insurance coverage are only part of the problem. Some parents are concerned about a "stigma" associated with hearing loss, and some children simply refuse to wear an aid.

But the most common deterrent is a failure to recognize a hearing problem in young children. Indicators include a delay in acquiring language, poor enunciation, failure to properly follow instructions and a tendency to turn the volume up on the television or sit very close to it.

Note: The above are excerpts from an article written by Jane Brody in the *New York Times* on December 8, 2008. To read the entire article log on:

**[www.nytimes.com/2008/12/09/health/09brod.html?ref=todayspaper](http://www.nytimes.com/2008/12/09/health/09brod.html?ref=todayspaper)**

## **News from Hearing Loss Association of America (HLAA)**

### HLAA Meets with President-Elect Obama's Transition Team, December 15, 2008

HLAA and other leaders from the community of people who are hard of hearing or deaf met with members of the Obama Transition Team December 11, 2008. Leaders at the meeting had worked hard to provide the Transition Team members with a consensus document on the issues impacting people who are hard of hearing or deaf. Transition Team member Kareem Dale welcomed us and made it clear the new administration would be looking for ways to ensure that all people with disabilities would have a seat at the table when decisions were being made that impacted their lives. It was an exciting opportunity to reach out to the new administration and make our voices heard.

The Obama-Biden Transition Team has put in place a remarkable online opportunity regarding how stakeholders influence public policy:

[http://change.gov/open\\_government/yourseatatthetable](http://change.gov/open_government/yourseatatthetable). The consensus document of organizations representing people who are hard of hearing or deaf should appear on that site in the coming weeks.

This site promises to show all the meetings they are holding with stakeholders, and includes links to materials those stakeholders are using in those meetings.

There's also an opportunity for the public to comment on each meeting and the issues raised.

### HLAA meets with Acting Surgeon General Steven K Galson, May 12/08, Washington, D.C.:

Brenda Battat, executive director of HLAA arranged for a meeting with acting Surgeon General Steven K. Galson to talk about the need for more public education about hearing loss.

HLAA invited six other stakeholder groups to join the meeting at which they stressed the need to start a public dialogue about the causes, impact on physical and psychosocial well being of untreated hearing loss, treatment options available, the stigma effect and the need to protect hearing from noise. There are 31 million Americans with hearing loss with 10 million resulting from noise exposure that could have been prevented but cannot be reversed. Hearing aids are effective devices but they are underutilized with less than 25 % of people who could benefit actually using them.

### Airlines

Hearing Loss Association of America is working for you. In recent meetings with the US Department of Transportation (DOT), HLAA learned that DOT is not receiving enough complaints from people with hearing loss. DOT needs to see your complaints. They cannot know what problems we face unless they hear from us. Complaints can be filed directly with DOT using their form found on the web: <http://airconsumer.ost.dot.gov/escomplaint/es.cfm>. Or take the HLAA airline complaint form with you next time you fly. Using the information you include on our form, HLAA will help you file your complaint. For more information, contact: Lise Hamlin.

Source: [www.hearingloss.org](http://www.hearingloss.org)

### What is HLAA?

HLAA is a national organization which advocates on behalf of people with hearing loss. Their \$25 membership dues include a bimonthly magazine, an online newsletter and message board. Visit: [www.hearingloss.org](http://www.hearingloss.org); 1-301-657-2246.

ICIC is a chapter of HLAA. HLAA dues are separate from ICIC donations.

Visit our website for latest information: [www.illinoisici.com](http://www.illinoisici.com)

## Online Discussion and Support Groups

*The discussion groups listed below are designed to help support those who are considering or already have a cochlear implant.*

Nucleus Forum: Online Peer Counseling and Support for the Cochlear Implant Community. It is operated by Cochlear Americas and is open to all CI users.

**[www.cochlearamericas.com/support](http://www.cochlearamericas.com/support)**

Beyond Hearing (Duke University): Discussion related to hearing loss; not just cochlear implants. Contact: **[majordomo@duke.edusending](mailto:majordomo@duke.edusending)**

Deafonline Forums: A discussion forum for Deaf, hard of hearing, late-deafened, cochlear implant users and many others to share information, thoughts, opinions, news and ideas on a variety of hearing loss or deaf related topics and issues: **[www.deafonline.org](http://www.deafonline.org)**

Hearing Loss Association of America (HLAA): Online message boards and chat rooms: **[www.hearingloss.org](http://www.hearingloss.org)**

Say What Club Provides lists of CI users to subscribers who have a CI or who are in the process of getting a CI and who want to share their experiences. For more information or to subscribe contact: **[info@saywhatclub.com](mailto:info@saywhatclub.com)**.

Yahoo CI Forum: A CI mail list is for everyone interested in cochlear implants. To subscribe send a message to: **[ci-subscribe@yahoogroups](mailto:ci-subscribe@yahoogroups)**

CIHear: Support for those who are interested in cochlear implants. To subscribe, send an email to: **[CIHear-subscribe@yahoogroups.com](mailto:CIHear-subscribe@yahoogroups.com)**

CI Family: An e-mail list for adults and parents who have a cochlear implant or are interested in a cochlear implant for themselves or their child. To subscribe send a message to: **[CIFAMILY-subscribe@yahoogroups.com](mailto:CIFAMILY-subscribe@yahoogroups.com)**

Yahoo CI Forum: A CI mail list is for everyone interested in cochlear implants. To subscribe send a message to: **[ci-subscribe@yahoogroups.com](mailto:ci-subscribe@yahoogroups.com)**

Hearing Exchange: a bulletin board that offers a variety of topics where members can post information and comments for others to read: **[www.hearingexchange.com/ubb/ultimatebb.cgi](http://www.hearingexchange.com/ubb/ultimatebb.cgi)**

*The above information has been adapted from a list posted on the Cochlear America's website.*

### **HLAA Convention, June 18-20 2009**

#### **Gaylord Opryland Resort and Convention Center, Nashville, TN**

Sign up for this special convention celebrating HLAA's 30th anniversary.

The convention offers many educational seminars, interesting exhibits and opportunities to meet others who share a life with hearing loss. The keynote speaker is Vint Cerf, Ph.D., a vice-president of Google. He is considered to be one of the "fathers of the internet" and will speak on technology and hearing assistance.

For more information and registration log on **[www.hearingloss.org](http://www.hearingloss.org)** and click on **"Convention."**

**ILLINOIS COCHLEAR IMPLANT CHAPTER**  
**Hearing Loss Association of America**

**2009 Membership Application/Renewal**

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_ Phone \_\_\_\_\_

e-mail \_\_\_\_\_ Fax \_\_\_\_\_

**Annual Donation.....\$25.00**  
Additional support..... \_\_\_\_\_

Please make check payable to: Illinois Cochlear Implant Chapter  
Mail to: Marc Siegel, Treasurer, 1415 Rose Blvd. Buffalo Grove, IL 60089

Date \_\_\_\_\_

**Please sign me up for one of the following committees:**

**1) Refreshments**

- > *Bring refreshments such as cookies, coffee, cold drinks, cups, plates, napkins, tablecloth, etc.  
(Costs will be reimbursed).*
- > *Set up table for refreshments*
- > *Prepare coffee*
- > *Clean up after meeting*

Name \_\_\_\_\_ e-mail or phone \_\_\_\_\_

**2) Program planning**

- > *Make recommendations to the board regarding speakers and other programs*

Name \_\_\_\_\_ e-mail or phone \_\_\_\_\_

**3) Greeter**

- > *Greet people as they arrive.*
- > *Welcome newcomers and introduce them to a member.*
- > *Take charge of sign-in table (sign-up sheet, name tags)*

Name \_\_\_\_\_ e-mail or phone \_\_\_\_\_

**4) Room setup**

- > *Arrange tables and chairs before meeting.*
- > *Return room to original condition after meeting*

Name \_\_\_\_\_ e-mail or phone \_\_\_\_\_

## **Future ICIC Meetings in 2009**

March 21st, 2:30 - 4:30, at the Morton Grove Park District

***"The Future of Cochlear Implants"***

Dr. Andrew J. Fishman, Implant Surgeon, Northwestern University Hospital

May 16th, 2:00 - 4:00 P.M. at the College of DuPage

***"Personality Responses to Hearing Loss":***

Liz Booth, ICIC member

July 18th 2:30 - 4:30, at the Morton Grove Park District

***"Pediatric CIs"***

Dr. Robert Battista, Implant Surgeon & Dawn Maniskas, pediatric audiologist:

September 12th or 26th, 2:00 - 4:00 P.M., at the College of DuPage

***"How to Maximize CI Mappings"***.

Dr. Miriam Redleaf, Implant Surgeon, University of Chicago:

November 21st, 2:30 - 4:30 P.M., at the Morton Grove Park District

***(1) The Americans with Disabilities Act as It Relates to Hearing Impairment,  
(2) Legal Rights of Employees with Hearing Loss, (3) Rights in the Courtroom***

Dr. Linda Remensnyder, audiologist:

### **Meeting locations:**

#### **College of DuPage, Glen Ellyn:**

Building K, room 131, Fawell Blvd. & Lambert Road (SW corner).

#### **Morton Grove Park District's Prairie View Center, Morton Grove,**

Dempster & Waukegan (one block east of Waukegan on Dempster. Turn north on Athletic Dr.)

***Real Time captioning is provided at all ICIC meetings***

## **ICIC newsletter**

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