

News You Can Use - - Join Us on July 18th!

Did you know that 17 out of every 1000 children under the age of 18 experience hearing loss? Newborn hearing screenings find that 1-3 out of 1000 healthy babies, and 2-4 out of 1000 babies in ICU are born with hearing loss. This is a bilateral loss in 1-2 of 1000 and unilateral in 4 of 1000 babies.

Left untreated, childhood hearing loss significantly impacts the speech, language, and psychosocial development of these children. The cost of educating a child with untreated hearing loss is ten times greater than that of children with normal hearing.

Meeting the fundamental hearing needs of children is a family decision. Cochlear implant is an option that allows a hearing impaired child access to sound along with many choices and opportunities. With a cochlear implant, they will learn to understand speech more quickly and more easily. So many of the beautiful sounds of our world will be accessible to these children at an early age, the chirping of birds, the lilt of parents' voices, the laughter of childhood, and the inspiring voices of teachers.

At our next meeting on July 18th Dr. Robert Battista, Implant Surgeon, & Dawn Maniskas, pediatric audiologist, of the Ear Institute of Chicago, will discuss **Bilateral Pediatric and Adult Cochlear Implants: Simultaneous and Sequential**".

Members of the "Child's Voice" school will then share with us the unique and exciting work done at their school to help children who have hearing impairments. 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. Many of the children at Child's Voice have cochlear implants. (Please see article about Child's Voice inside this newsletter.)

Please join us at the Morton Grove Park District, on July 18th to hear more about this miraculous gift that is available for children with profound hearing loss.

Hanna

Listening With Liz

The other day my husband asked me a question. When he got no response he asked if I had my processor on. I did not. It was early morning and I had not yet activated it to begin my day.

I often do this. Sometimes I enjoy the peaceful silence for a little while as I slowly greet the world. But once I engage my processor, it stays on until I am ready for bed at night. It successfully enables me to hear all the beautiful sounds of the world.

I have had my cochlear implant for eight years. Without it I am deaf. I cannot hear the kitchen timer beep, the dog bark, the telephone ring. Sometimes I forget my reality.

Because I am able to access information without too much difficulty, it is easy for me to take my new-found hearing for granted. Sure, I'll listen to that radio program, go to the movie, enjoy an evening at a restaurant. I'll grab my book and immerse myself in it while waiting for my name to be called at the doctor's office, not concerned about hearing my name called. My personal miracle has returned my sense of hearing and confidence to me.

However, when my husband asks me that morning question or my battery runs down, I am quickly reminded of my reality. I am deaf.

How amazing it is, this gift of hearing. It is difficult and, yes, almost frightening, to imagine life without my cochlear implant.

Oop's. I've got to go. My telephone is ringing and I can hear it. I will answer it with just a little bit of left-over trepidation since I will be able to hear the caller. Amazing.

Happy hearing.

Liz Booth

Minutes of ICIC Meeting

March 21, 2009

Edited by Liz Booth

“The Future of Cochlear Implants”

Presenter:

Dr. Fishman, Northwestern University Medical Center

Dr. Fishman is a cochlear implant surgeon at Northwestern in Chicago. He has been here for 18 months after training and practicing at New York University since 1996. He has an academic appointment in Poland in the Nicholas Copernicus Center where they will begin to do CIs. Dr. Fishman has also worked in south India at the Amrita Institute of Medical Science where he trained surgeons to do CIs and did skull-based neurosurgical procedures. Finally he has an academic volunteer appointment at the National Naval Medical Center in Bethesda, Maryland, where he has also done CIs.

In order to understand cochlear implants of the future, we need to understand how we got to where we are today. The cochlear implant works by substituting the normal hearing mechanism with an electrode placed next to the auditory nerve. The focus of Dr. Fishman's work has been on the electrode, a delivery system of the information to the cochlea.

Dr. Fishman used slides to show a number of electrodes that were studied and developed in a laboratory setting beginning in the 1990s. There are different ways to get the information into the cochlea. One example is the straight injector, one of the early Advanced Bionics electrodes. It goes in nicely and smoothly, relatively atraumatically, and the current electrodes still have a lot of these features.

Another slide showed an electrode that is straight and fed in by hand, a little bit at a time. That is a feature of our current electrodes. The reason he studied these electrodes was to see how they could get inside the cochlea with doing the least amount of damage to the delicate internal structures in hopes of optimizing the performance and keeping many nerves alive.

Another slide showed a straight electrode. There are frictional forces when placing such an electrode and that will cause a little bit of scarring and trauma from the insertion. This causes the little bit of hearing that is left to go away. A lot of work has been done to try to make that damage as absolutely minimal as possible.

Dr. Fishman's research group collaborated with engineers from three centers, New York University, one in Australia, and one in Germany, to develop a system that would be inserted as least traumatically as possibly. They also tried to get the electrodes as close to the nerves as possible, thus allowing a reduction of the amount of electric current that is needed to drive the system. These systems are similar within the devices of all three CI manufacturing companies, Advanced Bionics, Cochlear Americas, and Med-El Corporation. The slides presented were from Cochlear Americas.

Initially the electrode was introduced into the cochlea very slowly and once it was in, a little rod that allowed it to be close up towards the center was pulled out. The next thing that was added to make it even less traumatic during insertion was called a ski tip. Now it is called the advance and that lets it glide in even smoother without doing any damage to the outer structures.

So, this is the history of the development of this electrode from the various stages over about a 15-year period of time.

There is also one from Advanced Bionics called the helix electrode which works on a very similar principal; it comes off a stylet and goes in gently. In some patients residual hearing is preserved.

Most sensory hearing loss begins in the high frequency regions and then gradually progresses down, leaving the low frequency intact. The area of the cochlear that has the low frequency is the furthest part away from where insertion is begun. So when the electrodes are put in, they start in the location of the highest frequency which usually does not have as much residual function as the end part farthest from the electrode. If the electrode is put in very gently, sometimes that portion at the tip can be saved and that is very useful for the patient. If they combine the high frequencies that are given back with the implant with the residual low frequency that is still here, it gives a much broader spectrum of hearing. If they have that low frequency hearing in both ears, they still have some good directional information of their surrounding space which is very useful. So, it is a very high priority to do everything to preserve residual function.

This goes along with the development of surgical techniques which involve the tiniest little opening of the inner ear, and still allow safe insertion of the electrode without damaging the electrode. It is not very easy to put the electrode in very gently through a very, very small opening. Dr. Fishman showed a small clip of the Contour Advanced electrode being put in a patient in a fashion that does preserve residual hearing. The first step is to make a very, very small hole, about a millimeter in size. The bone is opened very gently. The electrode is held with jeweler's forceps and gently inserted with the metal rod feeding the electrode in a little bit at a time. The metal rod is then taken out.

This current state of technology at experienced centers with experienced surgeons using these techniques and electrodes, can preserve the internal function less than half the time. What is left over is not always the full amount that was there to begin with. So presently, the expectation is that residual hearing will most likely be lost. This is the reason why they are working to develop newer electrodes with a higher probability of saving residual hearing.

Dr. Fishman next addressed the hybrid system electrode which will happen in the near future. It has a hearing aid and the cochlear implant speech processor built in together to take advantage of the residual hearing and the implant in the same ear. Northwestern will be one of the test centers for the hybrid electrode study. It is a very, very thin electrode and a little shorter than the ones in the current devices. The rationale is that it does not have to get all the way up into the low frequencies, because the patients receiving this electrode will still have a larger amount of residual low frequency hearing. But the electrode is long enough to cover all the important speech and understanding ranges. The electrode has a little handle to deliver it and it will be inserted a little further away from the delicate structures that could be damaged.

Candidates for the hybrid system would be patients who are not satisfied with current hearing aids because of poor high frequency hearing, but still have enough low frequency hearing that would make them potentially not typical CI candidates. This thinner electrode would preserve what hearing is left, thereby expanding the criteria for patients to receive CIs. The ideal goal of future cochlear implants involves replacing what is not there and keeping what is there presently.

In order to qualify for the hybrid trial, the patient would have better than 60 decibels in low frequencies and about 75 decibels in the high frequencies. They would still have a fair amount of speech understanding. Only adults will be considered and they must have a word recognition

score between 10 and 60 percent in the treated ear. The contralateral should be better than the treated ear, but no more than 80 percent. These are strict criteria for the trial. For more information, you may contact Dr. Fishman, the center at Northwestern, or else Cochlear Corporation. Recruitment of patients is beginning. There will be compensation for patients' time, and will require in-depth testing for up to 18-24 months.

Looking into the distant future of cochlear implants, some things are being worked on right now which will be incorporated into far-off technology. Lasers are being used to stimulate the nerves. Differences between laser energy (light energy) and electrical energy are dramatic. Electrical energy spreads over adjacent tissues. Light energy travels in a perfectly straight line. In laboratory environments, they can almost stimulate an individual pitch with a straight line of laser energy. Another advantage of laser energy would be the ability to aim them toward the cells. Right now the electrode will make contact with whatever tissues are closest to it and we have very little control over the actual aim of that energy.

Presently implants are using between 8 and 22 channels. Lasers can be put through fiberoptic cables that are microscopic and through tiny little LED chips. They can potentially have thousands of channels. This would give very high resolution information. Right now we are not giving every bit of information of sound. We are just selecting enough channels to be able to recognize exactly what it is. Increasing the number of channels and resolution, that opens up a lot of possibilities when we think in terms of music.

There is a lot of media attention. Dr. Fishman is collaborating with Dr. Claus-Peter Richter at Northwestern. You can look at some of these articles on the Internet by looking up lasers, hearing, Richter, Northwestern. The company they are working with right now is Lockheed Martin. They are developing the stimulating lasers and the current experimental system is a tabletop unit, too big to get into a person. However, they are getting pretty close to something that could be implanted into someone.

There is a lot of work that needs to be done in terms of chips and programming. So this technology is at least five, ten, or more years away. People should not wait to get a CI because they think this laser technology is coming soon. That is not the case. This is really futuristic technology.

They are also looking into hand-held lasers to do the implant surgery. The laser can create a very tiny hole which cannot be done with a drill. There is the absolute minimum amount of injury to the structures underneath. This offers some potential to increase the number of patients who will have their residual hearing saved. There are side effects of lasers since heat energy is produced, so more study is needed.

Some people with a CI may be considering going bilateral. They may hear of these futuristic possibilities and think they should wait for that second implant. However, Dr. Fishman said that is not reasonable thought because the most important factor is the brain's ability to integrate the information that is being given to it. In hearing you are probably better off if you have similar kinds of information being given with bilateral implants. It might be unreasonable to expect the brain to do a very good job of integrating two very different kinds of implants down the road.

One of the advantages of bilateral implants is comprehension in noise situations. When the brain hears information it does a calculation of what is coming in both sides. It subtracts the bad information from the good information. The bilateral implant gives the brain the ability to block out the noisy information.

Dr. Fishman continued by addressing the totally implantable cochlear implant. This device already exists and has been implanted into some people. It has a microphone that picks up from under the skin. The miniaturized speech processor is built into it. It also has the antenna and the magnet. However, there is a problem. Battery technology has not caught up to implant technology. We cannot indefinitely recharge batteries, so everyone who underwent this particular implant knew it was an experimental trial that eventually would be exactly like a regular CI. They will have to start wearing the outer component because you cannot recharge the battery forever. That is the reason we do not have completely implantable implants yet. It has nothing to do with the implant technology, but everything to do with the energy requirements and the battery technology.

Dr. Fishman concluded by summarizing the future of cochlear implants:

They will probably replace only the hearing that is lost.

They will not damage the hearing that is there.

They will probably have no external components.

They will probably address the losses in both ears.

They will be integrated with fully implantable hearing aids.

They will probably operate on lasers and fiberoptics.

They will probably be MRI compatible.

They will probably be operated by atomic energy.

They will probably be implanted by robots

It will be quite some time before all this happens. We will see little pieces of it over the next few years into the future.

Minutes of ICIC Meeting

May 16, 2009

Presenter: Liz Booth, ICIC member

“Personality Styles of Response to Hearing Loss”

Liz Booth, a member of ICIC, offered a presentation and discussion on, “Personality Styles of Response to Hearing Loss.” Liz shared that she has been hearing impaired since the age of seven. Her loss was progressive and she began to wear hearing aids when she went to college. She received her cochlear implant eight years ago.

Hearing loss is a challenge that we live with 24/7. It is always with us and can cause us to give up, problem solve, or come out fighting. Many times our success or failure in dealing with difficult listening situations does not just reflect our hearing loss, but rather our attitude about our hearing loss.

Sometimes we make assumptions about what we hear, even though we know we are not quite sure that we heard correctly. Often our assumptions are wrong, but do not impact us in a significant way. However, sometimes our assumptions may be wrong about something very important, e.g. the time of a meeting, the dosage of a medicine, or the address of a job interview.

The consequences of these errant assumptions may be substantial. When we depend on our assumptions we are responding with a passive personality. We ask no questions and get no clarification. We do not communicate our hearing needs.

A passive communicator's thought patterns might be those of a stoic ("The hearing loss is mine. I don't want to inflict it on anybody else."), a martyr ("Poor me. There's nothing I can do about my hearing loss."), an avoider ("It's just too hard. I'll avoid every place that is difficult for me."), or a bluffer ("I won't tell anyone that I can't hear because they'll think that I'm flawed.").

A passive responder will often smile or nod and do what everybody else in the room is doing. He will be overly dependent on others to serve as his ears. He will have a vague expression on his face and will withdraw from most interaction because it is just too difficult.

By being passive you will miss opportunities, and experience frustration, isolation, inadequacy, and low self-esteem.

The opposite of a passive person who is hearing challenged, is someone who comes out fighting, ready to attack the speaker and blame all those around her. Her comments do not motivate the speaker to help make listening easier: "Don't you know it's rude to chew gum while speaking to someone?" "Can't you have brighter light in your home (or office)?" "Stop your mumbling and open your mouth when you speak!"

This is an aggressive responder. She is ready to blame anyone and anything else for her inability to hear. She will come across as hostile, and overbearing with a belligerent attitude.

Aggressive people try to dominate the conversation and cause resentment in other people by violating their rights. The end result of this type of response is frustration, isolation, stress, anger, a lack of cooperation, and missed opportunities. It is not an uncommon type of response because living with hearing loss is frustrating and challenging.

However, there is no winner in this type of confrontational response. The listener remains frustrated and angry and the speaker is angry, helpless, and confused

The better response is assertiveness. The person who communicates assertively admits he has a hearing loss, explains his needs in order to hear better, and does not blame anyone else for unsuccessful communication. He looks for a solution by being honest, open, and respectful of the speaker. He offers practical and specific suggestions to the speaker which will help him to hear better in any given situation ("Perhaps you could talk just a little bit slower." "Could we continue our conversation out in the hallway where it's more quiet?" "Would you please repeat that in a different way?"). You can give some periodic feedback to check your understanding, but try not to interrupt too soon.

The assertive listener empowers both members of the conversation. He does not violate the rights of others and is courteous. He recognizes the efforts of others and always expresses appreciation. When people understand the problem, they are usually very happy to do what they can to help.

As an assertive responder, you can ask the speaker not to say, "Never mind," or "It's not important," when you have missed something. Do not accept anyone telling you what is or what is not important. If something is important enough to be uttered, it is important enough for you to hear and evaluate its significance for yourself.

All of us respond in different ways in different situations. Sometime we are passive, sometimes aggressive, and sometimes assertive. It is good to be conscious of our response patterns and mindfully try to become more assertive in getting our needs met.

Life may not be the party we had hoped for, but while we're here, we should dance!

Technology Corner

by Ed O'Brien

Fire Safety at Night

As a cochlear implant user, I never get interrupted from an early morning noise or thunder at night. It is a luxury some of my peers envy. I have strobes and bed shakers for the phone, the door and of course my alarm clock. But if the fire alarm goes off I'm not going to hear it. It isn't going to wake me up. I'll just have to wait for the sprinklers to go off - that should wake me! I've seen special fire sensors made for the deaf. They will transmit to receivers, but I have five fire alarms hard wired into the condo building. It is both expensive and impractical to replace all of them.

At the last HLAA Convention I saw a prototype of new shaker alarm clock that listens for the distinctive sound a modern fire alarm emits. When it hears fire, it activates the shaker and the clock display changes to "FIRE". The new alarm clock is called the Lifetone HL. It costs about \$180 and includes a shaker. While not cheap, it does fill a void in my otherwise cochlear implant adapted home.

>> "Just Out! On June 12, the National Fire Alarm Code released a study that says the currently recommended strobe and tone designed to wake the HOH is not as effective as they hoped. The new requirement, effective in 5 years, is to change the tone to a lower pitch cycling sound and add a tactile device like a bed shaker so the deaf and profoundly HOH are alerted. The Lifetone device provides this now."

Theater Anyone?

Enjoy theater with captions at the Victory Gardens' Biograph Theater in Chicago,
The next captioned play is:

BLACKBIRD by David Harrower Starring - WILLIAM L. PETERSEN

Captions: July 29, 2 P.M.; August 7, 8 P.M.; August 8, 5 P.M.

Sign Language Interpretation: August 7, 8 P.M.

Victory Gardens Access Project is dedicated to providing a barrier-free theatrical experience. This includes Assistive Services such as captioned and audio-described performances; Sign Language interpreted, large-print and Braille programs; Touch Tours; wheelchair seating; and TTY phone lines. Captioning is provided by Caption First, Inc. The AudioLink Personal Listening System provides amplification on lightweight wireless headsets and features the ability to adjust for specific hearing needs. Please contact the House Manager to receive a headset. A form of identification is required as a deposit. Victory Gardens is located at 2433 N. Lincoln Avenue. Box Office phone: 773-871-3000. To receive the Access Project Newsletter please call: 773/549-5788, TTY 773/871-0682 or e-mail: information@victorygardens.org.

New Website to find Captioned Movies!

The following message was posted by Linda Belice, ALDA Chicago:

Captionfish provides captioned film results for the deaf and hard-of-hearing community.

By default, the Instant CC Film Finder™ gives custom results within 30 miles of each person's location for today. Plan ahead with our 7 day results. To improve its proximity results, please click on Change search. Go to **www.captionfish.com**

*This info is shared with you at the request of Marsha Kopp, ALDA, Chicago. Brendan Gramer, Chris Sano, and Greg Milliam from DeafCode made this possible! **Pass the word!***

Chapter News

ICIC members attend Convention of the Hearing Association of America (HLAA)

Two ICIC board members, Liz Booth and Ed O'Brien, attended the HLAA convention in Nashville Tennessee. Liz was ICIC's official delegate to the Convention.

>> Liz and Ed, we hope you enjoyed the convention and learned a lot.

ICIC Helps Young Adults to Attend HLAA Convention

The ICIC board voted to contribute \$500 from our 2008 Walk4Hearing funds to help support young adults who wish to attend the HLAA convention. The purpose is to help young adult attendees to live better with their hearing loss, help them grow personally and professionally, socialize with others who have a hearing loss, and more.

ICIC board Hires Professional to Coordinate Awareness Campaign

ICIC is dedicated to increasing awareness of hearing loss and its effects on people who have hearing impairments. To help with this endeavor, the ICIC board hired Scott Goldberg, a professional media person, to coordinate our awareness campaign. This effort is paid for by funds raised at the 2008 Walk4Hearing.

Walk4Hearing 2009 -- Save the Date!

Sunday, October 18th, 2009, 9 A.M., at Lincoln Park – Cannon Drive, 5K (3.1 miles)

Since 2006, thousands of people nationwide have joined the effort to end the stigma associated with hearing loss and provide support and resources for hearing loss prevention and education programs through the Walk4Hearing which is sponsored by the Hearing Loss Association of America (HLAA)

Last year's walk raised approximately \$72K of which ICIC realized the largest portion of the netproceeds of HLAA's portion. ICIC is using it's funds to raise awareness regarding the benefits of cochlear Implants for persons with hearing impairments.

This year the Chicago walk recruited Michael Orschein to be Business Team Chair responsible for recruiting sponsors. HLAA'S website is open for registration (individuals or teams) at: www.hearingloss.org. Ronnie Adler is the contact person at RAdler@hearingloss.org

Chances are you, or someone you know, is affected by hearing loss ----- Please STEP UP!!

What is the Illinois Cochlear Implant Chapter (ICIC)?

ICIC, a chapter 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.*

Hearing Loss Association of America (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 boards. Phone: 301-657-2248, www.hearingloss.org. Note: HLAA dues are separate from ICIC donations.

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_____

ICIC Meetings in 2009

July 18th 2:30 - 4:30 P.M. at the Morton Grove Park District

1) “Bilateral Pediatric & Adult Cochlear Implants: Simultaneous & Sequential”

Dr. Robert Battista, Implant Surgeon & Dawn Maniskas, pediatric audiologist
Ear Institute of Chicago

2) Presentation by “Child’s Voice” School

Members of “Child's Voice” will share the unique work done with children who have cochlear implants
“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.

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

"Positioning of the External Processor"

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

6316 Tamiami Drive
Downers Grove, IL 60516

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