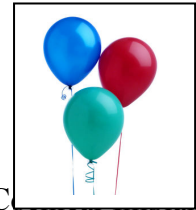


ICIC newsletter

Hear Here! ICIC is 20 Years Old!

Reflections on ICIC's Early Years

By Terri Lambert, ICIC's founder and first president



It is hard to believe that 20 years have gone by since the founding of the Illinois Cochlear Implant Club. It seems like yesterday that Dr. Richard Wiet and Audiologist Kathy O'Connor championed the formation of a group to provide access to technical-information-made-easy and personal support to potential implant candidates and their families. Being a patient of Dr. Wiet's, and having had my implant for over a year, he asked that I further develop, and then implement, the concept of a focused support group. I took up the challenge with great alacrity, knowing that I had my family to back me up.

Not knowing exactly where to start, it turned into a family affair – from my husband George to my children and grandchildren. At the time there was only one company that made implants, Cochlear Corporation. I was able to get a list of the people in Illinois with implants and sent out letters informing them about our goals for a support group – and so it started. We sent out meeting notices, secured a meeting room at the College of Du Page, made coffee and lemon bars – and they came. They came from all over the Midwest, from Illinois to Iowa to the Upper Peninsula of Michigan.

The first meetings were formative in nature. We spent a good deal of time discussing our “stories” with each other, learning to support each other, and refining our message of understanding and support. We were fortunate over the years to have had many eloquent speakers who were able to bring the complex and rapidly changing technology to us in understandable terms. Because of the willingness of our members to give of themselves, we had a very cordial atmosphere for visitors seeking help with their decision to get an implant. It was common for the one-on-one conversations between I.C.I.C. members Sheldon Azriel, or Ted Burtzos, and a potential implantee to last until the coffee was put away, the room cleaned, the chairs stacked, and the lights turned out.

The initial meetings were truly a family affair from room set-up, to greeting and name tags, to passing out information, to baking sweets, to note taking, to clean-up. We eventually got a little more sophisticated with captioning, formal agendas, and varied presentations; but the underlying goal of providing support to those with a cochlear implant, and those contemplating a cochlear implant, remained the same.

Although it started small, with the help of those initial *members the seed has grown*. I am blessed to have been a part of the formation and a member of the journey.

Minutes of ICIC meeting

March 20, 2010

“The Psychology of Hearing Impairment

As it Relates to Cochlear Implants”

By Dr. James Vanderbosch

Dr. Vanderbosch is a clinical psychologist with 30 years of experience working with deaf children and adults. He currently works primarily with children in three therapeutic group homes in Northbrook. The children are deaf and all the work is done in sign language. Many have cochlear implants. He has done extensive work with DCFS.

There are approximately 26 or 27 million deaf people in the United States and about 33% of them experience some type of mental illness at some point in their lives. This is 4-6 times the rate of the general population. They tend to get physically abused at 4-5 times the rate and suffer from serious addictions at 4 times the rate. They are diagnosed with retardation mainly because they did not get what they needed when they were young.

These are not acute psychiatric disorders, but mostly problems with character, an Axis II disorder, a failure to develop important personality skills between the ages of 0 and 5. 75-80% of parents of deaf kids never learned sign language so they couldn't establish a bond with the young children and didn't have information about deafness. The child does not learn about frustration tolerance, communication, good self-esteem, or a sense of right and wrong. These delays in personality skills cause a struggle when they begin school.

Children that were born hard of hearing or began to lose their hearing at 6-8 years old have different types of problems. Are they deaf or are they hearing? By early adolescence they often choose to be deaf because it's easier for them to sign. They might feel like a one-eyed man in a blind world. In the hearing world they hide their disability and struggle with communication. There is more depression and anxiety in this population as well as in adults who start losing their hearing late in life. They struggle with loss of relationships, disengagement with their family, and become isolated and struggle at work.

Some of the children that Dr. Vanderbosch works with have other disabilities along with deafness. They may have processing problems or attention deficit disorder. Sometimes the cochlear implant has confused the boundaries between deaf and hearing. He evaluated children for cochlear implants when the FDA first approved implantation in 3-year olds.

Dr Vanderbosch commented that many people do not go into cochlear implantation knowing what to expect. That's one of the benefits of groups like ICIC. When people get cochlear implants they have to relearn how to hear and hear in a different way. Everybody adjusts in a different way.

People should seek professional help if they are losing sleep, if there's a change in appetite, if they are feeling depressed or moody or irritable, and it persists over a period of six weeks.

Dr. Vanderbosch kindly answered many questions from the membership.

The American Disabilities Act (ADA)

As It Related to Persons Who Have A Hearing Loss

By: Tonia Bogener

Ms. Bogener is the legal counsel for the Illinois Deaf and Hard of Hearing Commission. The Commission is a state agency begun in 1996 in Springfield with seven staff members. Before working with the commission Ms. Bogener worked for the attorney general's office in the disability rights bureau.

Communication access, the primary barrier faced by people with hearing loss, can be confusing. People do not understand why some people lip read, some need sign language, some use written English. They are confused when they are told that hearing aids and cochlear implants do not restore normal hearing. This means that when trying to get service from an employer or a public entity, there is a lot of work and education to do.

The American Disabilities Act was adopted in 1990. It is a federal disability law that prohibits discrimination based on disability. There are five parts or titles, but the predominant three are employment, state/local government, and public accommodations.

Title I, Employment, covers employers with 15 or more employees. The point is to give you the same equal opportunity in your job as anyone else from hiring, the application, the interview, advancement, staff meetings, trainings, and social events. Necessary accommodations must be provided.

Title II, state and local government, prohibits discrimination in such areas as public meetings, presentations, educational programs, and meetings with public officials. You have the right to receive your choice of accommodation whether it is CART, an FM system, etc.

Title III, public accommodations, covers private entities in 12 categories such as doctors, lawyers, theaters, museums, and libraries. There are tax credits. Private membership clubs and religious entities are exempted.

It is up to you to request the accommodations that you need. Timing is important since often plans have to be made ahead of time. It is also important for you to document requests and responses. Providers need to be educated and many are still unaware of legal responsibilities.

The Commission is an advocating body and will empower you and give you the tools to request the accommodation. If it is denied they will help you; however they have no enforcement authority over a federal law. The Department of Justice has a complaint process and mediation. Those are steps before filing a lawsuit. Ms. Bogener will personally get involved when possible and offered members her business card. She shared other additional resources: The Great Lakes Technical Assistance: 800-949-4232 (www.adagreatlakes.org), the US Department of Justice (www.ada.gov), and the Center for Independent Living (<http://www.incil.org/>).

Other laws include the Illinois Human Rights Act, the Federal Rehabilitation Act of 1973, and the Interpreter for the Deaf Licensure Act of 2007.

Ms. Bogener stressed that the important message is we have to be assertive in seeking the accommodations we need.

Submitted by Liz Booth

>>>> *More ADA information:*

Job Qualification Testing

Hearing Loss Association of America Position Paper

Can an employer lawfully require its employees and applicants for jobs to take a hearing test and screen out those who fail to pass? Does an employee or applicant who has a hearing loss have the right to use hearing aids while taking such a test?

Hearing loss is a disability within the meaning of the Americans with Disabilities Act (ADA). This statute, as amended in 2008, clarifies that the use of hearing aids does not cause individuals with hearing loss to lose their rights under the law. The ADA prohibits an employer from applying a job qualification standard that screens out or tends to screen out disabled persons.

However, an employer can require employees and applicants to pass a hearing test if the employer can demonstrate that the requisite level of hearing proficiency is job related and a business necessity. This showing can be made for a number of different jobs, but it is often asserted where performance of the job may result in a direct threat to the safety of the employee or other people. Jobs in law enforcement and fire fighting are examples where employers have successfully met this standard.

The question of whether the ADA provides employees and applicants with the right to use hearing aids while taking a hearing test remains unsettled under the law. For example, the Department of Justice in carrying out its ADA enforcement responsibilities has maintained that individuals must be evaluated on a case-by-case basis, both for those who use hearing aids and those who do not. Consistent with this guidance, many state and local police officers as well as guards at nuclear facilities may use hearing aids during hearing tests. However, in recent court cases, it was concluded that employers may lawfully bar individuals from using hearing aids while being tested.

It should be noted that aside from the rights of employees and applicants to use hearing aids during testing, individuals with hearing loss have a responsibility to suggest reasonable accommodations that would enable the employee or applicant to meet a hearing proficiency job qualification standard. For example, a school bus driver with hearing loss showed that installation of a mirror to view students at the back of the bus and use of an aide at busy times would enable her to monitor students while driving safely.

However, for many law enforcement positions, for example, such as police officers on patrol, a reasonable accommodation may not be available in all circumstances. It is imperative that individuals holding or seeking these types of jobs have the right to be evaluated with hearing aids. They have no other way to demonstrate their capability to perform these jobs.

It is the position of the Hearing Loss Association of America that employees and applicants who use hearing aids must be tested with their hearing aids when determining their qualifications for jobs where a level of hearing proficiency is a legitimate criterion. Although there have been no court cases beyond the use of hearing aids, it is our position that employees with cochlear implants or other implantable devices should be tested with the implants on.

Adopted by the HLAA Board of Trustees, March 6, 2010

For further information, contact Advocacy@hearingloss.org

Chapter News

HLAA Convention, June 17-20, 2010

Several ICIC members, including all ICIC board members, will attend the HLAA convention. ICIC will have a booth at the convention. We are proud and honored that two of our members, **Tina Childress** and **Liz Booth**, will be convention speakers. Please join us. You can come for the entire convention or just for a day. Topics include Advocacy and Access, Hearing Technology, Medical Issues, Relationships and Communication, and Young Adults. For more information and registration visit www.hearingloss.org/convention

ICIC's On-line Store

Visit our on-line store where you can purchase clothing and goods with the ICIC logo. The items are made to order by CafePress. Proceeds from the store will be used to support ICIC and its mission. Log on our website www.illinoisci.com and click on the CafePress logo. Just click on [Store](#) or use the link on the left side bar.

Board of Directors News

Unfortunately, **Liz Booth** had to resign from the board as she and her husband moved to Arizona to be closer to their children. However, we are happy to report that Liz will continue to be a member of ICIC. Thankfully, Liz will continue to write her popular column "Listening with Liz", as well as summaries of our meetings, for our newsletter. Here's some of what Liz said in her letter of resignation: *"I have enjoyed my 9-year tenure with the ICIC board and have found the work with the board of directors to be challenging, rewarding, and personally fulfilling.... ICIC is a vibrant, respected, and effective chapter of HLAA. It has offered support, information, connections, and friendship to so many people and will continue to do so. Know that your work is vital and appreciated."*

Thank you, Liz for nine good and productive years on the ICIC board! We appreciate your leadership, knowledge, friendship and especially your sensitivity to the needs of persons who have hearing impairments. We look forward to your continued involvement with ICIC.

>>> Dear members, please let us know about achievements and/or recognitions for yourselves or others. We want to share the many good things that our members do.

What is ICIC?

The Illinois Cochlear Implant Chapter (ICIC), a member of the Hearing Loss Association of America, is an organization for cochlear implant (CI) recipients, prospective recipients, professionals, and other interested parties. We offer information and support to help current CI users as well as to prospective users and their families. At our meetings we offer presentations by experts such as CI surgeons, audiologists and CI company representatives. ICIC strives to increase awareness of hearing loss, and promote the benefits of cochlear implants.

As a member organization we depend on annual contributions of \$25 to cover expenses. Expenses include captioning services, room rentals, printing, postage, insurance, web hosting, A/V equipment, promotion, outreach and more.

We welcome input from our members. Thank you.

Listening With Liz

This morning I slowly awake to a beautiful Arizona morning. The sun is bright and the overhead fan lazily and silently makes its turns. There are birds outside the window chirping their silent songs, and our dog is chasing them with silent barks.

As I make my way through the morning routine, the shower silently spews its warm water, the electric toothbrush silently does its work, the coffee-maker silently brews its wake-up elixir, and the toaster silently pops forth breakfast.

I wander through the house and watch as my husband silently types on his computer and the morning TV celebrities silently chat. The ever-present construction in our brand new neighborhood is silently underway.

And I experience the peaceful quiet that so many of you share with me. Before donning my hearing aid and cochlear implant for the day, the silence that surrounds me is almost a poem of peace. I can greet the day without the jarring jangle of immediate disruptive sound. I can quietly and slowly gather my thoughts before entering into the busyness of my day.

You all have heard the adage, “When life gives you lemons, make lemonade.” I think these quiet, serene mornings are one big glass of lemonade in my life. My wish for you is peace in the silent moments of your own lives. It is a hidden blessing of our hearing loss.

Tech Corner

By Ed O'Brien

Is My Cell Phone Ringing?



I'm one of those lucky people who can talk on a cell phone in a quiet setting without too much trouble. But I do have one annoying problem. I often don't hear my phone ringing while it is buried in my pocket. I try setting it on vibrate, but that doesn't seem to work either. I've even been tapped on the shoulder in public places to be told my phone is ringing. What to do?

I've recently come across this interesting wrist band that will vibrate when my phone rings. It even has a display to show me who's calling. They're called Bluetooth bracelets. You can find them online by that search term. I found them priced between \$20 and \$75.

Did You Know?

Hybrid hearing aid/cochlear implant

Electric Acoustic Stimulation (EAS) is a hybrid treatment solution for individuals who have some hearing left in the low frequencies but who cannot hear all of the higher frequency sounds. The EAS-implant is a combination of a hearing aid that acoustically amplifies low frequencies and a cochlear implant that electrically stimulates the higher frequencies.

Chemotherapy for testicular cancer causes hearing loss

Men in a study group who had received high-dose cisplatin-based chemotherapy were more likely to have long-term problems with ringing in the ears and hearing loss. Additionally, men in the study who smoked on a daily basis were more likely to have hearing impairment than the men in the study who never smoked. The study was carried out at Haukeland University Hospital in Bergen, Norway.

Hearing loss affects psychosocial health, particularly in young people

An extensive survey found clear associations between hearing loss and feelings of loneliness, distress, depression, anxiety and somatization. Young people are more deeply affected than older people.

Healthier hearing in the baby boomers

The hearing of the post-war generation - the baby boomers - is better than that of their parents. That is the conclusion of an American study, which shows that the rate of hearing impairment in baby boomers is in fact 31% lower than that of their parents.

A gene that can cause hearing impairment

A gene involved in our hearing is called claudin-9. When that gene suffers a mutation, the result can be hereditary hearing problems.

>>> *Read complete texts of above articles on: www.hear-it.org*

Early Surgery Best for Children With Hearing Loss

Inserting cochlear implants early significantly improves spoken language comprehension and expression in young children who have severe hearing loss, a new study shows. The younger the children were when they underwent cochlear implantation, the greater the improvement. Read complete article on: www.nlm.nih.gov/medlineplus/news/fullstory_97989.html

Information from the Illinois Secretary of State's Office

Emergency Contact Database

The Illinois Secretary of State's office has a new database which allows Illinois driver's license or permit and ID card holders to enter emergency contact information into a voluntary, secure database. In an emergency, law enforcement personnel may access this database to help them reach designated emergency contacts. Log on www.cyberdriveillinois.com or call **1-800 252-8980**.

"J88" - Deaf/Hard of Hearing Driver's License

"J88" is a notation on a driver's license that alerts law enforcement officers before approaching a vehicle that a motorist is deaf or hard of hearing. You can request that the "J88" notation be added to your driver's license at any Secretary of State Driver Services facility. "J88" will appear on both the front and back of your driver's license. Include your driver's license number on your vehicle registration to link the two together.

"HI" - License Plates for the Hard of Hearing

"HI" license plates are issued to drivers with a Type 4 hearing disability or as provided in Section 4A of the Illinois Identification Card Act. A certification form must be completed and signed by a licensed physician. Applications may be obtained at most Secretary of State Facilities, or call 1-800-252-8980.

Movies & Theaters Accessible to People with Hearing Impairments

Movies: Check these helpful links to find captioned movies near you:

www.mopix.org - theatres that list accessible films and show times on their sites

www.captionfish.com - search for captioned, subtitled and/or described films based on your zip code

www.fomdi.com - search for captioned films by zip code

www.deafaccessfilms.com - search for captioned films based on zip code



Theaters: A listing of accessible theater performances is available on the website of the Chicago Hearing Society: www.chicagohearingociety.org

Source: The Chicago Hearing Society

Chicago Hearing Society

The Chicago Hearing Society offers a wide array of programs and services to the Chicago metropolitan area's deaf and hard of hearing community: www.chicagohearingociety.org

Walk for Hearing 2010

Save the date for the 4th annual Chicago Walk4Hearing on October 16, 2010 in Lincoln Park.

Last year's walk raised nearly \$100K easily exceeding the goal of \$85,000. This year the goal is \$125K which can be met by getting the word out to your friends, families, businesses, etc.

Join Team ICIC, or start our own team, and become part of a growing national event for a cause that is near and dear to our hearts. Half of all money raised on behalf of ICIC will go towards ICIC's Community Outreach programs which includes, but is not limited to walk sponsorship, scholarships, potential tuition support, and raising awareness of hearing loss.

So grab your walking shoes and join the Walk4Hearing on October 16, 2010 in Lincoln Park.

Marc Siegel, Chicago Walk4Hearing Treasurer

Cochlear implants improve quality of life

People who receive a cochlear implant become better able to recognize speech and their self esteem increases, as well, according to a German study. The study also found that the changes resulting from implants benefit the recipients' social interaction.

Fifty six people with cochlear implants were asked to evaluate their ability to recognize sound, speech recognition, self-esteem and social interaction. All of the participants had at least 12 months experience with their implants following an average of 10.2 years of hearing loss. Fifty of the 56 respondents stated that they were always or mostly satisfied with their cochlear implant.



Source: Otolaryngology – Head and Neck Surgery, 3/08

2010 Meeting Dates & Topics

Next Meeting:

Saturday, May 15th, 2:00 – 4:00 P.M. at the College of DuPage, bldg. K, room 131

1. Assistive Hearing Devices for Individuals Experiencing Hearing Loss

By: Michelle Maher, HITEC, Naperville

HITEC is a leading provider of telecommunication products for the hearing impaired

2. Update on Advanced Bionic's Cochlear Implants, by Kerry Roech

Saturday, July 17th – 2 P.M. -- Garden Party at Hanna Benioff's home

Celebrating ICIC's 20th Anniversary &

Information Fair with Representatives from Cochlear Implant Manufacturers

Saturday, September 11th 2:00 – 4:00 P.M. - College of DuPage, room 131

1. "What the Hearing Loss Association of America (HLAA) Does For the Hard-of-Hearing/Cochlear Implant Community"

By: Dick Meyer, former HLAA president

2. Update on MedEl's Cochlear Implants, by Pam McGuinty

Saturday, November 20th, 2:30 – 4:30 P.M. - Morton Grove Park District

"Updates on Current Cochlear Implant Design and Technology"

By: Dr. Richard Wiet, implant surgeon, and an audiologist, Ear Institute of Chicago

Meeting locations

College of DuPage: Fawell Blvd. & Lambert Road, Glen Ellyn (SW corner) Bldg K, Rm 131

Morton Grove Park District's Prairie View Center: Dempster & Waukegan. One block east of Waukegan on Dempster, Morton Grove (turn north at the light on Athletic Drive)

Real Time Captioning is provided at ICIC meetings by "Caption First"

HLAA Convention, June 17 – 20, 2010

Hilton Milwaukee City Center and Midwest Airlines Center

Register now! You can come for the entire convention or just for a day.

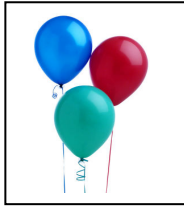
Presentations include: Advocacy & Access, Hearing Technology, Medical Issues, Relationships & Communication, and much more.

Register at www.hearingloss.org/convention

Visit our website at: www.illinoisci.com

Hear Here! We are 20 years old!

Mark Your Calendars!



Join us on

Saturday, July 17th at 2 P.M.

To Celebrate I.C.I.S.'s 20th Anniversary

At a Garden Party & Information Fair

At Hanna Benioff's home, 6316 Tamiami Drive, Downers Grove

*Representatives from three Cochlear Implant Manufacturers
will share information about their cochlear implant products*

Please come! Bring friends and family to celebrate our 20th birthday.

Refreshments

Handouts

Good Cheer

This and past newsletters can be found on our website: www.illinoisci.com

ICIC newsletter

6316 Tamiami Drive
Downers Grove, IL 60516

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

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