

www.illinoisci.com benioff0@gmail.com 630-964-1229

March 2013

ICIC Meetings

Saturday March 16

2:30 – 4:30 pm Morton Grove Park District's Prairie View Center

"OUR CI STORY"

Janet Tusk, moderator

A panel of CI recipients discuss their experiences

They will then answer questions about their CI experiences

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Saturday May 18, 2pm College of DuPage

1. "How to Communicate with Your Audiologist"

By Pam Fiebig, audiologist Dr. Alan Micco, Implant Surgeon Northwestern University, Chicago

2. Update from MedEl

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Communication Strategies with Tina Childress

A recap of ICIC meeting held 11/19/2013. Edited by Janet Tusk

Tina Childress, an educational audiologist who lives and works in Champaign, IL, has a very unique perspective as a practicing audiologist who became deaf due to autoimmune inner ear disease and subsequently received bilateral cochlear implants. As such, she knows intimately the issues that face cochlear implant recipients as well as understanding them through an audiologist's professional eyes.

Communication Strategies for Gatherings: (restaurants, parties, reunions, meetings, etc.)

These environments have many challenges including lots of people in noisy spaces who are often eating and drinking, conversation topics that change frequently and unpredictably, and people you don't know with unfamiliar speaking styles. Often, folks are talking over each other and speaking louder in general to compensate for the noisy atmosphere. What can we do to optimize our understanding in these situations?

Let's first address the intrinsic factors (things we can't control or change about the environment). First up is **acoustics**. Large rooms with hard surfaces, homes with open floor plans and great rooms all pose acoustic challenges to comprehension. Options we might exercise include closing doors or partitions to segment the space, moving to a smaller room if possible, and avoid sitting near busy areas like the kitchen or entrance.

Another big factor to address is **lighting**. Position yourself so the light is behind you so the faces of those you are speaking with are illuminated, enabling lip-reading. You <u>do not</u> want to sit facing a window or light source, with the light and glare in your face. If candles are on the table, move them to the side to keep them from shining in your face.

If you're able to choose a venue or restaurant for a gathering, keep these tips in mind to improve acoustics: Carpeting is preferred over hardwood flooring or tile. Acoustic ceiling tile is preferred over a tin ceiling or lofted space. Booths segregate conversations better than open tables. If only tables are available, choose round tables versus a square or rectangular so everyone is visible.

If one ear is better than the other, make sure your good ear is facing the majority of the table or group. If possible, sit with your back to a corner or wall to minimize noise from behind. Clearing the field also helps you to focus on the speaker: if possible, move centerpieces, condiments, menu holders, etc. to the side or floor.

The most effective strategy in any environment is to get close to whomever you want to speak with or the sound source you want to focus on. In addition to being physically close to a speaker, we can use technologies that bring the sound closer to us.

Technological strategies include using assistive hearing technology (in addition to or in concert with our cochlear implants). FM systems and looping can bring the sound directly to your ear by utilizing the telecoil in your implant. These options are expensive however, and not covered by insurance, and looping requires installation around the perimeter of the area, so it may not be feasible for temporary use.

Less expensive technological strategies include using a lapel or auxiliary microphone that can be held by or clipped to the speaker. Many people have smartphones or tablets; these can be used like an electronic notepad and the speaker could type into it. If a data signal (telephone or wi-fi) is available, there is an app called *Google Translate* that uses voice recognition technology to transcribe voice to text and the resulting text size can be adjusted as needed.

Many factors can't be controlled, but we can always control our reactions to challenging listening environments. Our reactions are often dictated by our self-identity, or how upfront or reluctant we are to reveal our hearing loss and ask for things that may improve our comprehension. Depending on the situation, there are a number of strategies that can be used if you are open about what accommodations might help you.

When meeting new people, keep in mind that first impressions are important, and how you tell someone you need an accommodation can really make a difference.

Don't apologize when disclosing your hearing loss or asking for accommodation. It's a blameless situation and apologizing often makes the other person feel bad. Just state the facts. For example, say "Because of my hearing loss, it would be really helpful if you could ______." It allows the other person to be at ease because they now know how to help you. Always give them positive feedback and thank them for their efforts.

Some of the ways you may ask them to help include minimizing gesturing or avoid covering their mouth. Ask them to keep from talking while chewing gun or eating and to talk at a normal rate and volume (maybe a little slower and a touch louder, but not SHOUTING.) Not to speak at your back or while they're walking away, etc.

In a group, try taking turns speaking while using a totem (a ball, a microphone, etc.) that signifies who is speaking. This allows you to visually follow the speaker and assures only one person at a time is speaking. Ask people to raise their hand before speaking or to advise of a change of subject. Of course, using these methods means you have to be up-front about your hearing loss and needs. Another strategy is to have a "listening buddy"; a spouse, family member, or friend whose voice you're familiar with and who will help you out by repeating questions or joke punch-lines, giving clues to words said, saying things differently, or writing notes down. Understand that this puts a lot of pressure on them, so before you enter a social situation with them, be clear about just how much help you want them to provide. Different situations may call for varying levels of help.

Because a listening buddy knows you, they may be the first to pick up on changes in your hearing or comprehension. Don't discount their comments that something has changed or is wrong and get it checked out. Trust them and thank them for mentioning it.

Take good care of your device: Change your microphone covers on a regular basis, use a Dry-N-Store or Zephyr container at night to store your processor, keep batteries charged and available, use the appropriate settings for the situation, and get map checks regularly with your audiologist.

Sometimes, despite your best efforts, your reaction to communication stressors may be to bluff. Social bluffing is a kind of defense mechanism and is normal – hearing people bluff too! You just get tired of always asking for repetition, of reminding people to face you, or to speak slower, etc. When this happens, it's perfectly acceptable and you are fully entitled to take a "listening break".

If you're tired and frustrated, you're just not going to hear as well and simply removing yourself from the situation for a while can help. At a party or gathering, ask to help in the kitchen or do the dishes. Take a bathroom break, or move to a quieter section of the house or room if possible. Take a short walk and do something non-listening related. Take off your implant and just decompress for a bit. At home, with family or friends, make sure everyone is aware of the "house rules" of communicating effectively. Don't speak or yell from another room or level; go to them and talk face-to-face. Post signs or notes as reminders around the house. For some people, a letter might be helpful. Dr. Neil Bauman has a letter available you can download and alter as you wish. His "Dear Family" letter is available at http://www.hearinglosshelp.com/articles/PDF/dearfriend.pdf

Tina wrapped up by giving an update about captioning that is now available at various entertainment venues. The *Broadway in Chicago* live theater series now offers captioning at select performances. Shows such as *Les Miserables* and *Book of Mormon* at theaters in downtown Chicago are included. In the future, captioning may be available on demand at any performance! Other live theaters that offer captioning at select performances include *Steppenwolf* and *Victory Gardens*. For movies, be sure to check out http://www.captionfish.com (available as an app for smartphones too!) Just enter your zip code and it will list all the captioned movie offerings in your area. The various theater chains in the Chicago area offer different types of captioning devices. These include CaptiView; a small LED screen on a gooseneck that fits in the cup-holder, Sony Access Glasses; glasses to wear that display the captions, Rear Window captioning; an acrylic cup-holder panel device. Some theaters still offer open captioned showings as well, where the captions are displayed right on the main screen.

Finally, Hanna took the floor to thank Tina for her years spent as an ICIC board member and presented her with a plaque in appreciation.

Listening With Liz

By Liz Booth

I recently moderated a meeting that was to deal with issues of living with hearing loss. There were probably fifty people in attendance, most of whom had been challenged by progressive hearing loss for many years. I was intent on assuring everyone that the meeting would be fully accessible to them.

And, so, I mentioned CART. CART? CART? What is CART? Over half of the attendees had never experienced CART or even heard of CART.

And, then, I asked everyone to turn their telecoils to the "on" position if they had T-coil. Telecoil? What is a telecoil? Why do I need a trelecoil? Too many device-users were unaware of telecoil technology.

Finally, I explained that the room had an induction loop to help with listening. Loop? Where's the loop? What's the loop? Loop America? Huh?

A few days earlier I had attended the theater. When I adjusted my assistive listening device which had small earphones, the person next to me asked what it was. He was wearing hearing aids and shared how live theater was often difficult for him to hear. He was previously unaware of ALDs.....and he ran to the desk to get his device before the curtain came up.

Neckloops? Infrared? Open captions? Closed captions? Caption Call? CapTel? Huh? And catalogs full of other devices......

Some of us are quite sophisticated in our knowledge of helpful technology that is there for the asking. We have learned of our many options by attending support groups, hearing presentations, sharing with others, researching on our own, attending conferences and conventions, visiting exhibits, etc. We are lucky enough to have the resources at our fingertips.

But, too many people with hearing loss suffer constant and needless frustration because they do not know of this assistive technology. That's where we come in. It is our role, our job, our calling to EDUCATE those that do not have this necessary knowledge. We must SHARE what works for us. We must MENTOR those that need to learn of ways to ease the frustration, withdrawal, and loneliness of hearing loss. We must INVITE them to our support groups.

This is important work. Go to it!



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What is ICIC

The Illinois Cochlear Implant Chapter (ICIC) is a not for profit chapter of the national Hearing Loss Association of America (<u>HLAA</u>). We are a support group that offers individuals who face a common challenge the opportunity to seek out emotional support and practical help in dealing with a major life change. We provide an atmosphere of caring, sharing and support in times of need, most importantly during the implant decision process. We do this by having meetings on Cochlear Implant related topics six times a year, by publishing a newsletter for members and maintaining a web-site. The chapter is run by and for its members.

<u>Membership</u> fees are \$15/year due at the beginning of each year. It does not matter when you joined or started coming to meetings

Real-time captioning (CART) is provided at every meeting. Every word spoken by speakers and group members is typed and projected on a large screen for everyone to see.

Who provides captions at ICIC Meetings, and what is CART?

CAPTION FIRST has been providing realtime captioning at ICIC meetings for the last 22 years. From day one, we have had a special relationship with CAPTION FIRST. Pat Graves, the company's president was actually our very first captioner. She was a member of ICIC and continues to be an avid supporter. Now, captioners Jo Gayle and Catherine Rajcan continue to provide a wonderful service.

Thank you CAPTION FIRST, and members of your staff, for your good and dedicated services. We appreciate your friendly and efficient service.

What is CART? -- CART stands for Communication Access Realtime Translation.) CART is a service in which a certified CART provider listens to speech and instantaneously translates all the speech to text.

How does CART work? The CART provider receives an audio feed. Using a steno machine and cutting-edge software, CART providers "write" on their steno machine using phonetic shorthand that they have gone to school to learn. The phonetic shorthand is then translated against the CART provider's dictionary. The software finds the associated word in the dictionary with the phonetic shorthand stroke written on the steno machine, translating instantaneously into English. CART providers can be certified to type up to 260 words per minute with 98% accuracy and above.

Visit our website at www.illinoisci.com

You will find much useful information such as Captioned Movie Listings, Chicago Area Implant Centers, CI Manufacturers, CI Accessories, What You Should Know about Cell Phones, General CI Information, and more.

HLAA Convention 2013: Mark your calendar!

This year the convention will be in Porland, Oregon June 27 -30

Congratulations, Tina Childress!

Exciting news! Tina Childress has been chosen as one of twelve finalists in the Oticon Focus on People Awards with the goal of changing negative stereotypes of what it means to have hearing loss. Tina is one of three audiologists in the Hearing Care Practitioner category.

Tina writes: "It's hard to believe that almost 14 years ago I started the journey as someone with hearing loss. In that time, my path has crossed with so many wonderful people who inspire ME and make me want to be a better clinician and advocate.

Some of you knew me before this time, some met me as I started down the path of a hearing aid user and eventually a bilateral cochlear implant recipient. I feel so blessed to be able to navigate both worlds - as a consumer and as an audiologist - and help others realize their hearing potential or help others hear or communicate at their best."

We are proud of you Tina. OTICON could not have nominated a better person. We at ICIC have been fortunate to have you as a member, board member, resource person and popular lecturer.

Way to go Tina!

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

ICIC Board of Directors

Hanna Benioff, President Ed O'Brien, Website Editor Jessica Melton Marc Siegel, Treasurer Janet Tusk

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