

HLAA TC

NOVEMBER 2013



The mission of HLAA TC is to open the world of communication to people with hearing loss by providing information, education, support and advocacy.

November 10, 2013

Cochlear Implant Social group (see details inside)

November 16, 2013

HLAA TC Chapter Meeting. Speaker - Kristin Swan, psychologist with Health Partners: Hearing Loss Challenges around the Holidays

December 8, 2013

Cochlear Implant Social group three-year celebration (see details inside)

December 21, 2013

HLAA TC Chapter Meeting: group discussion and Holiday Party. Don't miss it!

January 18, 2014

HLAA TC Chapter Meeting: Speaker Mary Hartnett, MCDHH Legislative update and overview

February 15, 2014

HLAA TC meeting: Marty Barnum: Nursing Homes and Hearing Loss Issues

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Hearing Loss Association of America Twin Cities Chapter (HLAA TC) is held the 3rd Saturday of the month (except June, July and August). We meet at The Courage Center, 3915 Golden Valley Road, Golden Valley, MN 55442

President's Message



President's Message October 2013

By Monique Hammond

There is a lot more to hearing loss than not hearing well!

During our October meeting we learned once more about the diverse issues related to hearing loss. Our speaker, attorney Rick Macpherson of the MN Disability Law Center, gave us valuable information about communication access concerns. He also shared some practical tips for securing the accommodation that we need. Later, MCDHH executive director Mary Hartnett asked for our stakeholder input as the Commission decides on priority issues for the next five years.

Yes, there is a lot more to hearing loss than not

hearing well and our mission statement speaks to that fact: To open the world of communication to people with hearing loss by providing information, education, advocacy and support.

At HLAA TC we all are both students and teachers as we ask questions or share a personal experience or piece of information. Together we learn about the multi-faceted condition called hearing loss in a non-threatening and respectful environment.

Although some of the material or speaker topics might not seem to address our very own personal issues or interests every single time, there is a lot of room for learning. As I have found out over the years, ALL information is relevant and applies to us - now or later. I have never walked away from a meeting yet without having had some Aha-moments. Yes, we learn for our own benefit but we also learn so that we can enlighten others on issues of hearing loss. Finally, we learn so that we may become more effective advocates, And the world of hearing loss needs plenty of those.

Knowing that we are not alone, we gain the confidence to stick up for ourselves in a variety of circumstances: By calling TV networks and political campaigns to report captioning issues; by asking that an employer, place of worship, museum or theatre install a hearing loop; by heeding the Commission's calls for us to contact our elected officials when legislative actions could affect us adversely. These are all examples of advocacy. We are there and we count!

Hearing loss is also fraught with emotions as we know all too well. **On Saturday, November 16, psychologist Kristin Swan** will be our speaker. She is specialized in working with those with hearing loss. She talked to us some years ago and brought great insights and solace to the group. Don't miss her – just before the Holiday Season, a time that can be quite trying for us.

Until we meet again, stay safe and enjoy the change of Seasons.

Monique



HLAA TC Meeting October 20, 2013

Synopsis by Christine T. Morgan

President Hammond called the meeting to order, and alerted us to a scam where people are calling those with IPCTS (Internet Protocol Captioned Telephone Relay Services) and asking questions. They also want to come to your house. The FCC is asking that you report any such calls to the FCC's Disability Rights Officer (202-559-5158). If you have a captioned relay service and somebody calls and asks for information, do not answer. Instead, call the people who installed it for you.

President Hammond read her quote for the day from Nelson Mandela: "Education is the most powerful weapon that you can use to change the world." Knowledge enables us to become more powerful speakers in our community and to be able to do something about the bias and stigma that is still attached to hearing loss.

President Hammond then introduced Rick MacPherson who is an attorney with the Minnesota Disability Law Center. Rick represents people with disabilities and has a special interest in dealing with people with hearing loss. He is a recognized expert and has gotten awards for his work.

Rick distributed brochures explaining what the Disability Law Center is and how to contact them. He also passed out surveys on what their priorities should be, what legal help might be needed and how they can best use their resources.

The Disability Law Center is a non-profit, partially funded by the federal government and other groups. They provide free legal services to people with disabilities throughout Minnesota. They also handle discrimination cases. They mostly handle cases where people have problems getting access to services (government, medical, legal), or getting physical access to buildings, businesses, etc. They do not handle employment issues.

To make sure you are getting the kinds of assistive devices you need to have effective communication with doctors, hospitals, the court, etc., make sure you notify the entity in advance about your needs. Your chances of getting what you need (such as CART) are then greater. Rick advised us to state that we "need" (as opposed to "prefer") to increase the likelihood of getting appropriate accommodations.

In the medical area, it is a good idea to contact the people that run the clinic or hospital that you go to on a regular basis. Talk to them about your needs. Counter loop systems would be very helpful in medical facilities and in pharmacies. Organizations such as HLAA could approach pharmacies on behalf of their members. If that doesn't work, HLAA could approach the Disability Law Center to determine if they are violating the law. The violators may then have to pay a penalty.

The ADA, the Minnesota Human Rights Act, and The Federal Rehabilitation Act all have requirements to provide the devices that will ensure effective communication. Enforcement, however, depends on people with disabilities insisting on what they need.

Right after the break, President Hammond stated that HLAA-TC begun talks with Courage Center about looping our meeting room permanently. We hope to have this done before the year is out.

Kim Fishman is setting up a small committee for looping the in Twin Cities. The committee would meet once a month at Chears, 5808 West 36th Street, St. Louis Park, MN 55416.

President Hammond introduced Mary Hartnett, the Executive Director of the Commission for the Deaf, DeafBlind and Hard-of-Hearing Minnesotans (MCDHH). It is a 15 member, Governor-appointed commission that advocates for equal opportunities for Minnesotans with hearing loss, and hearing and vision loss. Mary is here to gather input into what priorities they should focus on for the next five years.

Some of the past five year accomplishments were the Newborn Screening Hearing Bill, deaf mentors who teach in the home for those parents who teach sign language at home to their babies, a hearing aid bank so babies get immediate amplification, parent guides, captioning of all state website videos. There's also an online course called "Video Online Captioning Essentials", an online course that teaches people how to caption their own videos, and another online course on how to advocate for medical accessibility in doctor's offices, emergency rooms, etc. One course teaches why it's important to vote and how to get access in your voting booth. The Commission created an online website called "Deaf Rights". They also have an employment task force that's working on trying to get rid of bias within state government. Last year the legislature gave the Commission additional funds to hire more staff to get more work done. Surveys were sent out to those on the e-mail list.

Mary commented that the laws and regulations are on the Commission's website under "Deaf Rights." The 400 rules are listed and you can print them off. The legislators want to hear your stories about hearing issues and lack of access. The four advocacy groups that the Commission works with are Minnesota DeafBlind Association, HLAA, Minnesota Association of Deaf Citizens and Hands and Voices.

After a lengthy discussion, Mary is going to let the Commission know that it is important to strengthen consumer protections in the hearing aid law, making sure that audiologists and hearing aid dispensers include and educate people about T-coils, aural rehabilitation, looping, etc. Also making sure that manufacturers don't get a lock-in at different facilities and that there be consumer choice.

Mary asked people to sign up on the Commission's e-mail list as well.

Bob asked for volunteers for the Steak Fry, which will be held Wednesday night April 9th, 2014. He also reminded everyone that dues were due in September.

Lionel will be calling members to verify information that we have in our system within the next 30 days.

President Hammond adjourned the meeting.





View from the underground (Bob)



Meeting Snapshots



President Monique, and speakers Rick McPherson and Marv Hartnett chat





Monique opens the meeting



Mary is back!



Mary Hartnett takes the stand



If “language is at the true core of what makes us uniquely human” (*Keys to Raising a Deaf Child*, quoted in Guthrie program book), then what makes us human is both much better and much worse than the things that connect us to the rest of the animal world.

Much of the language in Tribes (by Nina Raine), which Dennis and I attended at the Guthrie Theater, is not of the sort that you or I would welcome in our home. It is the language of a dysfunctional family, each member cherishing his own delusions while also in some measure recognizing them for what they are.

Billy, younger son of Beth and Christopher, and sibling to Daniel and Ruth, is one of those members, and yet not one of them. He is adept at speechreading, and yet he admits later in the play, that most of what he does is guess – in one instance with disastrous results.

Billy was born deaf, but raised in a hearing household where he was not taught sign language, which his family made no attempt to learn. His girlfriend Sylvia on the other hand, was born hearing and raised in a signing household. Sylvia at first would seem to have the better deal, being capable of communicating in two languages, where Billy has expertise in neither. But Sylvia is *becoming* deaf, arguably a more challenging and traumatic experience than being born that way.

The play makes many good points, and reveals some truths about being hard of hearing and deaf. One statement that caught my attention was Sylvia’s defense against the charge that ASL is just “broken English”: “If you translate literally from *any* language, it will sound like broken English.” That is an argument I hope to remember, should the same challenge be put to me.

It makes a great quote. But good drama is more than a list of good quotes. Drama should show us through the characters those truths it wants to impress on us. To some extent, Tribes does this. When Sylvia turns her back on being deaf, seemingly rejecting the very language and culture that has been so liberating to Billy, we are prepared for it. We realize, if we didn’t before, how much she has to lose.

Billy has been through the loss already. Or rather, he began with one type of loss – hearing loss – and in dealing with that, experienced another. Both Billy and his family suffer from the alienation between them.

In the end, there is a reconciliation of sorts, and one feels that ultimately there will be reconciliation on other levels, the most important perhaps being that Billy and Sylvia too are recognized to be “uniquely human”. And their language, ASL, is at the “true core” of that.

Vicki Martin

Working While Dealing With Hearing Loss



By Christine Morgan

Those of us with hearing loss all have a story. I didn't always realize this.

My hearing loss came on gradually about 10 years ago. It was mild and about 9 years ago, I got my first pair of hearing aids. I was amazed how much I heard with them. However, I still was embarrassed that I needed them and therefore, I kept them covered by my hair.

Gradually, my hearing got worse. I had to ask people to repeat things. I could only hear on the telephone (both cell and land line) with my left ear. Still I didn't let anyone know.

When my ear specialist put me on steroids, it helped my hearing temporarily. I hated the side effects and especially the "moon face" but people knew I had an auto-immune disease so figured that's why I was on steroids .

Through all this, I was working as a medical group administrator. That had been my career for over 20 years and I loved what I was doing. At this time, I was working with a fairly large group. Still I never told the doctors or most of the staff that I had a hearing loss. It made it very difficult when staff members and employees came up and whispered to me. I was too embarrassed to tell them that I didn't hear a word. So I pretended. I picked up a couple of their words and tried to understand the message.

The worse times were when I was having our monthly board meeting with the doctors. We held it in the waiting room of one of our clinics. We spread out in a large circle. There were often many conversations going on at the same time, not to mention noises as they opened and consumed their box lunches and drinks. Once I realized that one of them was speaking to me, I almost always had to have them repeat it. It was frustrating to me and I'm sure they often thought I was not paying attention.

Despite two rounds of high dose steroids, my hearing continued to deteriorate. In October 2010 at our board meeting, I decided to take the "bull by the horns". I explained to the group that I had a hearing loss most likely due to the auto-immune disease. I simply could not make out what they were saying to me, especially when several people were talking at the same time. I also explained that a cochlear implant might be in my future.

One would probably assume that medical professionals would be compassionate and understanding. And, honestly, some of the doctors were. However, there were at least a couple of "influential" ones in the group who seemed annoyed with me even though I asked for no accommodation. They would make a sarcastic comment or intolerant face when I asked them to repeat something. They knew the cost of a cochlear implant and all it entails. I believe a major concern was the impact on our group health insurance. A couple had made negative comments about the high medical care utilization of several

employees and staff with chronic or acute illnesses.

My job changed. I was treated differently than I had been for the previous 8 plus years. The joy went out of my job and frustration set in. I was sorry I had spoken up.

In May 2011 my first grandchild was born. I had told my son and his wife that whenever they had a child, I would quit and provide care. I left my position in June of 2011.

I then started reading about hearing loss. I learned things I wish I had known much earlier. Early in 2013, I found HLAA-TC. I met such wonderful, courageous people.

Am I still ashamed or embarrassed by my hearing loss? I'd like to say "no". But when I took that leap and told the doctors in 2010, it had such negative impact that I was sorry that I spoke up.

I am getting better about it. I now tell health care professionals and doctors who are providing my care, immediately that I have a hearing loss. I often even tell store clerks, TSA agents, etc.

Still, I often pretend to hear when I don't. Obviously, I still have a long way to go.

PS. Caring for my granddaughter is the best "job" in the entire world.

Holidays...Happy or Horrible??

By Judi Swan

With the upcoming Thanksgiving, Christmas and New Years' Holidays looming, it brings to mind the stressors of years past.

I have been making little notes to myself to remind me what I need to do to be a part of the activities and find some sense of inclusion.

Last year, a few moments come to mind that were really hard, and actually ended in a migraine for three days. I said then....

"Never again, I need to handle this better, and teach people that I matter, and I have needs."

So I began practicing when with one person, then two and then three and finally a group. I am finding who really cares about my hearing handicap and who does not. I am also finding that, sadly, I have to cut some of those out who don't consider my needs enough.

Sitting through something that I have no idea of what's going on, just isn't good enough for me anymore.

Call it getting older, and hopefully getting wiser. Call it wisdom, call it what you will, but for sure, it is going to be my way of life, because I have a choice. And I plan to exercise that choice and end up with a much more fruitful and happy existence as well as enjoy the holidays and all other social times to the fullest.

I don't mind missing a word here or there, or a joke, because even hearing people don't hear every part of every conversation due to distractions and overwhelming noisy situations.

In learning to demand respect, in a kind loving manner, I am finding that my peers and family want to know that and want to have me involved in the occasion.

Two main things I require when with others is to be in the least noisy environment of the room, and the other is to be not facing the person who has backlighting or a window that prevents me from seeing their face. Just these two things alone have been absolutely marvelous in my endeavor to communicate.

"Out of the Hands of Babes" (Pioneer Press Bulletin Board September 26):

Prairemom of Oakdale writes:

Talk about “total communication”! Our only grandchild, hearing daughter of a hearing dad and deaf mom, is being raised bilingually: English and American Sign Language. Her mom Amber set up a sort of reverse “pen” to keep 18-month-old Nora out of the kitchen while she was cooking, and Nora did not like that one bit. But Grandma and Grandpa got a chuckle out of the video her mom posted: Nora crying on the other side of the gate, stomping her little feet – and *signing* “cry”. I guess she wasn’t taking any chances that Mommy might miss this important message!



Adult Cochlear Implant Social Group!!!

Sunday, November 10, 2013 12:30-2:30 PM

Augsburg Park Library

7100 Nicollet Ave.

Richfield, MN 55423

612-543-6200

Please send your RSVP to Joe Sehl

Email: bionick@hushmail.com

You are welcome to bring a spouse, partner, friend, family member, and/or significant other to any of these events! If you would like to bring a refreshment to share that would be wonderful!

Also – coming soon...

Sunday, December 8

Special! -- 3-year celebration

1:30-3:30 on Wentworth Library in West St. Paul



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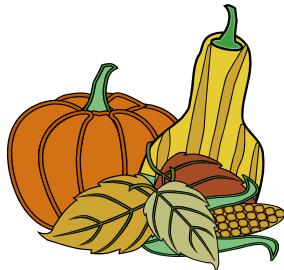
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This month's editor is Vicki Martin

Meetings are held the 3rd Saturday of the month September through May at the Courage Center in Golden Valley, MN. We gather at 9:30 to socialize and the meeting starts at 10 AM. All meetings are real time captioned by Lisa Richardson and her staff of *Paradigm Captioning* (www.paradigmreporting.com). Please visit the chapter's web-site at www.hlaatc.org or visit us on Facebook: groups/HLAA-TC.