

HLAA TC

December 2016



Twin Cities Chapter

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

Next Speaker:

December 17 2016

Kristin Swan, Health Partners
Behavioral Health on Hearing
Loss and Relationships

December meeting Includes:

Holiday party and pot luck
Cookie Sale
White Elephant Gift exchange
Silent Auction
(all at December 17 meeting)



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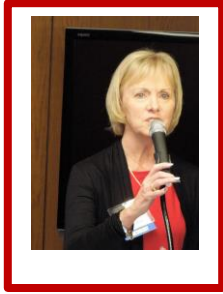
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Hearing Loss Association of America Twin Cities Chapter (HLAA TC) is held the 3rd Saturday of the month (September thru May). We gather at 9:30 to socialize, and begin our meeting at 10 AM at The Courage Kenny Rehabilitation Institute, 3915 Golden Valley Road, Golden Valley, MN 55442. The meeting adjourns at noon.

President's Message



Christine Morgan
December 2016

At the risk of sounding like a broken record, “where did the year go?” Does that just happen to us as we get older?

Here we are right smack in the middle of the holidays! You either love them or hate them. Sometimes both, depending on the day and/or time. The holidays are always a challenge for us with hearing loss. And did I mention the noise during the holidays? Ugh! It seems like we are being constantly being bombarded. Sensory overload. Yikes! I sound like Scrooge!!!!

Many of us have had a year that included deaths of our loved ones, illnesses, job losses, progressive hearing loss and numerous other blows that test our mettle (that’s a word from times past). But we manage to persevere with our chins up and smiles on our faces. Life with hearing loss has taught us well. One of my favorite sayings: that which does not kill us makes us stronger!

Just in time for the holidays, we have a guest speaker this month speaking on

relationships and hearing loss. Kristen Swan is a psychologist with HealthPartners, has many years of experience dealing with people with hearing loss, and we are fortunate to have her with us this month. Those who have heard her speak before know that she approaches these issues with humor, sensitivity, and a deep well of knowledge.

We also have our laughter and fun (not to mention food) filled annual holiday party. Please do bring your family and friends. All are welcome. It’s our chance to celebrate each other and all the new friends and acquaintances we have made at HLAA-TC.

I am so very thankful for every one of you. And I look forward to many more years together.

Warm regards for a wonderful, safe holiday season,

Christine



HLAA-TC Meeting Synopsis

November 19, 2016



Kathleen Marin, Vice-President

Christine Morgan called the meeting to order at 10 am and introduced the speaker, Dr. Tina Huang, a neurotologist at the University of Minnesota who presented on the topic of Meniere's disease. Dr. Huang stated that Meniere's presents as 4 symptoms together: vertigo, hearing loss in one ear, and fullness and increased tinnitus in that ear. Because vertigo and balance issues are so important, she reviewed the different types and causes of dizziness and imbalance. Vertigo is an inner ear-related dizziness in which it feels like everything around a person is moving, perhaps spinning, bobbing or weaving, while he or she is still. It may or may not involve imbalance. Imbalance, or disequilibrium, is the sense of feeling unsteady when one walks, like he or she may fall down, or walking like one is drunk without having consumed any alcohol. Lightheadedness is the sense of feeling imbalanced within oneself, like the head is floating on a string above the body, and may include presyncope, which is the sensation or warning that a person is about to pass out. This is not related to the inner ear.

Balance may or may not be related to the inner ear. Balance is achieved by the inner ears, the eyes, and nerves in our body, with everything coordinated by the brain. Much time is spent in the evaluation to determine the source of difficulties in balance. If true vertigo exists, the length of time it occurs is important. If it is very brief, only 30 seconds or less, it is most likely due to benign positional vertigo, the most common cause of dizziness in the adult population. If it lasts for days, it is probably not inner ear related. Vertigo associated with Meniere's lies between these 2 extremes.

The main test for Meniere's is the VNG, where the patient wears a set of goggles that makes everything fuzzy so they can't use typical visual cues for balance. The medical staff look for specific side to side movements of the eyes during activities like following a light bar, having warm and cold water squirted into the ears, and being placed in a rotary chair, to detect vertigo.

Meniere's is actually quite uncommon. It affects less than one half of one percent of the American population. No one knows for sure yet what causes it. The current theory is that fluid builds up in one of the compartments of the inner ear until the membrane actually tears, the fluids mix causing acute spinning, hearing drops due to damage to the cochlea, and then over time, the hole seals and the process starts over again.

Based on this theory, the treatment is to remove the excess fluid. That is done by a stringent salt restricted diet and a diuretic, or water pill. It is often helpful to keep a food diary, as people may have specific triggers as well. It is important to note that the treatment is for vertigo only, with the goal being to reduce the frequency and severity of attacks. There is no treatment yet for the hearing loss, other than use of hearing aids. Meniere's is a progressive disease and hearing is likely to erode over time.

(HLAA-TC October 2016 Meeting Synopsis, cont.)

If the standard medical treatment doesn't control the episodes of vertigo, there is a list of increasingly invasive approaches that can be used. The first is steroids, either oral or injected directly into the ear. They may even help bring back some lost hearing if there was a sudden drop. The next is a Meniett device, which puts pulses of pressure into the ear through an ear tube. It works about 50% of the time and, like steroids, no one knows why. Surgery may be an option for some people, specifically an endolymphatic sac decompression. This involves opening the sac, which is part of the lining of the brain and holds the inner ear fluid, providing a way for the extra fluid to come out. It works in about 70% of people, with the hope that the ear comes to some kind of an equilibrium after the hole closes back up. It may be effective for several years or only a few months. Another surgical technique is to actually cut the vestibular, or balance, nerve to completely take out the balance function on one side. The idea is that it is better to have just one functioning ear than to be sending conflicting signals to the brain. The success rate is 85% but recovery is long and much balance therapy is needed. Another technique to take out the balance function is the use of Gentamycin, an antibiotic that is injected directly into the ear every 2 to 4 weeks. The goal is to kill off enough of the balance function to prevent getting the spins while still preserving all or most of a person's hearing. If a person has no usable hearing, defined as less than 50% word understanding, then they can use Gentamycin daily to kill the cochlea or have the labyrinth removed surgically. That has about a 95% success rate at stopping the vertigo, but takes away any residual hearing that a person may have and requires balance rehab.

After the break, the board and members talked about: fund raising through the Walk4Hearing (including changing the date and venue and getting more publicity) and a steak fry in May (including getting members to sell 200 tickets and volunteer to help serve); developing an annotated list of helpful websites or blogs (please let Kathleen know of any that you find particularly useful); captioning at movies; a packet for people with hearing loss who will be in the hospital; and a reminder of the silent auction, cookie sale, potluck and white elephant gift exchange at our next meeting. The meeting was adjourned at noon.

THE LION IN WINTER

Guthrie Theater

Set during Christmas 1183, *The Lion in Winter* tells the wickedly amusing story of King Henry II, his imprisoned queen, and their three entitled sons as they vie for the throne. It's an epic family takedown, just in time for the holidays.

Open Captioned

Friday, December 16 at 7:30 p.m.

Wednesday, December 28 at 1 p.m.

Start the New Year right!

Improve your balance

Tai Chi class

Apple Valley Senior
Center

January 12 at 10 a.m.

Led by Christine Morgan

Free

December Guest Speaker:
Kristen Swan
on
Hearing Loss and Relationships



Kristen Swan

Kristen Swan received her BA from the University of Minnesota-Duluth in Communication Disorders, and her MA in Family Social Science from the University of Minnesota-St. Paul Campus. She has worked with deaf and hard of hearing people for over 40 years in a variety of capacities.

She worked for 10 years at Bread of Life Lutheran Church for the Deaf as the parish worker. She worked as the Project Director of the Supervised Apartment Living Training (SALT) program where she worked with adult deaf persons with independent living and mental health concerns. She served as the Family Therapist at the Minnesota Chemical Dependency Program for Deaf and Hard of Hearing people at Fairview Riverside Medical Center. In the fall of 1990, she rejoined the behavioral health staff at St. Paul Ramsey Medical Center - now called Regions Hospital - to take on the duties of Administrative Supervisor and Psychotherapist in the Health and Wellness Program serving Deaf and Hard of Hearing people.

She currently works with deaf, deaf blind and hard of hearing individuals, couples and families of all ages. She is a licensed psychologist, has traveled throughout the state to provide direct psychotherapy services, and also provides face-to-face therapy services through video conferencing. She has facilitated a number of therapy and psycho-educational groups for deaf and hard of hearing people including depression, relapse prevention, hard of hearing support and dialectical behavior therapy.

She has spoken at a number of conferences and events on issues related to hearing loss and provides in-services and consultations within the state.

Silent Night....er, I mean, Auction At December meeting



Our First Annual Silent Auction

December 17, 2016

Our Board and Chapter members have obtained an amazing array of donations. Some are from individuals and others are from different organizations and establishments.

Here is a sample of what we have received so far (with more to come as we get closer to the date):

Gift certificates from the Guthrie, Mixed Blood and History Theatres; a gift certificate from Patrick McGovern's Pub in St. Paul, a Curling Session (from our own Curling Coach) for 2-4 people, tickets from Carmike Oakdale, St. Paul Omnitheater..... just to name a few. It promises to be a lot of fun and with a frenzy of bidding.

SPECIFICS: Cash or check accepted. Unfortunately, we are unable to take credit or debit cards. You do not have to be present to win but, of course, once you leave, someone could outbid you. The auction will close at 11:30 a.m. and winners can pay and pick up their treasures at that time. If the winner is not present, the Board will make arrangements for payment and delivery shortly after the meeting.

So be sure to check out the items. You may come home with a bargain. At the same time, you are supporting your Chapter.

Christine

Let's Go to the Movies!

Kathleen Marin

After an informal poll in our last meeting revealed that at least two thirds of our members do not go to movies, I decided to do something about it. I interviewed managers at 3 theaters, each of which has a different system for captioning, to learn how they work and how best to access accommodations. Here is what I found out, both from the interviews and my own research.

CaptiView

Carmike Oakdale has consistently had the best reliability for captions in my experience, so I met with Dan, a manager. Carmike, like most theaters, uses the Dolby DoReMi CaptiView system, which consists of a small screen with 3 lines of dialogue and privacy visors so as not to disturb other patrons. It is attached to a flexible neck that fits into the cupholder. Each unit costs a few hundred dollars and works seamlessly with the Dolby system already present in the theater. There is a wireless unit above each projector that sends the captions to the units. The units can be programmed for whichever auditorium we are in and physically adjusted to just about any position for ease of viewing.

At Oakdale, the devices are kept in the manager's office and only the managers are trained in their operation. They are given to patrons fully charged (they are hooked up to the chargers all the time and have a battery life of about 16 hours) and programmed and ready to use. The managers are supposed to check on the patrons once the movie has started to make sure the captioning is working. Captioning does not usually start until the movie starts, so it is hard to know if the system is working. CaptiView units typically display "CaptiView ready" when you walk into the theater. If they still show "searching" as you enter the theater, they will not work and you need to go back to the manager to have them reset. So far, I have never had that happen at Oakdale, but have experienced it at other theaters. Carmike Oakdale has had captioning for about 3 or 4 years. They also offer assistive listening devices (ALDs) but only with headphones, not with loops. Surprisingly, they only get 1 request per week for captioning, almost always on the weekend, and usually the same patrons.

Sony Access Glasses

Regal Eagan has my favorite system, Sony's Entertainment Access Glasses, so I met with their general manager, Star Zoveral. This type of captioning is a pair of glasses attached to a receiver that is the same as for ALDs. There is a captioning track on the hard drive of movies which is transferred wirelessly to the receiver and from there is displayed on the lenses. It looks like the captions are floating about 10 feet in front of you. The brightness and location of the captions can be adjusted on the units. The glasses are delivered to us already programmed and ready to use. We can wander around the theater, buy popcorn, etc. before entering the auditorium and they will still work. When you enter the auditorium, the glasses will display "CC ON." If you don't see this, let a manager know and they will get you a new set. All employees are trained in the use of the glasses and are encouraged to watch a movie with them to know what it is like. Regal Eagan has 20 sets.

(Movies, cont.)

The glasses cost \$3,000 each and the receivers \$600. They have had captioning of some sort for at least 13 years, and the glasses for about 3 years. They started out with 10 sets and ran out during certain movies, so they bought more. They also have two CaptiView units and ALDs with loops and headphones. If they are not busy, we can use both glasses and ALDs simultaneously.

Rear Window Captioning

The Omnitheater at the Science Museum of Minnesota uses yet a different system, which the technical manager Chris Demko explained to me. It is Rear Window Captioning and is almost old fashioned but very reliable. A CC file is put into the sound computer and thus is in sync with the soundtrack. The captions project backwards onto a giant board at the rear of the theater. We view them on a clear acrylic screen which is covered with a reflective material and works like a mirror. The screen is mounted on a gooseneck stand that also adjusts for height so we can position it in the most comfortable manner. The unit has written instructions attached to it, plus an associate will explain how it works. Moreover, an associate watches the captioning at the back of the theater and watches the CC patrons to make sure everything is working. When we get in the theater with the device, we simply adjust the screen until it reflects the lights from the back of the theater, which are just above where the captions will be displayed. The theater associates are all trained in the use of the devices, initially shadowing an experienced employee, and watching a movie using captioning.

The Omnitheater has offered this type of captioning since it opened in 1999. It also offers ALDs with both loops and headphones, and translation into Spanish if the movie provides it. We can use both ALDs and captioning if we want. They get about 1 to 2 requests for captioning each day. Chris suggested that we request captioning when we make the reservation or at the box office. If we forget, we can talk to the person at the questions desk near the entrance to the Omnitheater. We will then go up to the 6th floor where an associate will give us the device and let us into the theater early so we can sit in the middle, which is the best spot for viewing captions.

Each theater has a different process for issuing captioning devices. Some, like AMC, give them out at the front desk; some, like Carmike, ask for your driver's license and then a manager brings the set to you; and some, like Regal, have you sign out the devices at a desk inside the theater. No matter what, you request captioning when you buy your tickets. The software has improved noticeably in the last few months. A major design flaw was that the captioning did not start until the movie started, so there was no way to know if the device would work or not. Now, most of them have some indication that they are programmed for the auditorium, and they are also captioning at least one trailer so we know they work. If the device doesn't work, or you are not sure, contact a manager to get a new one. And if you end up missing part of a movie, be sure to get a free pass to come back and try again. One final note: there are usually at least a few lines of dialogue that are not captioned. It appears that is a problem with the captioning track in the movie itself, and is often worse with low budget films.

There will be passes to the movies and to the Omnitheater and science museum at the silent auction. This will be a great opportunity to try out captioning at perhaps a lower price than usual. So let's start taking back that part of our lives that we've given up. Let's go to the movies!

Visiting the Brave New Workshop

Christine T. Morgan

This is going to sound like an opening for a mystery novel: on a cold, sleeting Tuesday in November (the 22nd to be exact), Christine, Kathleen and Lionel met with BNW. I know I said Acme Comedy Club at the last chapter meeting but, alas, I was confused on the name. I personally have never been to a comedy club. Improv is very difficult when one has hearing loss. However, I set up the appointment via e-mail and there was a glimmer of hope!

Of course, they have ASL but let me show you a picture of what they told me they had for an assistive listening device. I explained to them the many reasons why this is not adequate accommodation for those of us with hearing aids and cochlear implants.



After e-mailing back and forth, I set up the meeting for us. The three of us probably explained more about hearing loss than they ever wanted to know. When we left, I'm pretty sure I heard a sigh of relief. Bottom line: between my first e-mail and our meeting, they obtained a workable assistive listening device with its own loop. You need to have t-coils to use the loop (or some other device if you don't have t-coils).

Kathleen tried it with her hearing aids and I tried it with my implant processors and it does work. Hurray! They are going to determine how many ALDs they are required to have according to the ADA.

We also talked to them about the possibility of captioning and referred them to Jon Skaalen of VSA. This accommodation may not happen because of logistics when one is doing improv. All in all, it was a successful meeting and we were pleased when we went back on the icy Minnesota streets.



November Meeting



DECEMBER 17 – DON'T FORGET!

Speaker Kristen Swan

Pot Luck lunch

Silent Auction

White Elephant gift exchange

Cookie sale

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Our next meeting is December 17, 2016

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Meetings are held the 3rd Saturday of the month September through May at the Courage Kenny Rehabilitation Institute 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.