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Volume 33, Number 5 published monthly except July and August – Rochester NY Chapter Newsletter January 2020

JANUARY Calendar

Tuesday, January 7th

10:00 am – HOPE Session–Vestry Room, St. Paul's
“Hearing Other People's Experiences”

Daytime Chapter meeting:

11:00 am - Refreshments/Social Time- Parish Hall
11:30 am – Announcements
12 Noon – 1 pm – Program Speaker

Evening Chapter meeting:

7:00 pm – Refreshments/Social Time – Parish Hall
7:30 pm – Announcements
8:00 pm – 9 pm – Program Speaker

Tues., Jan. 14th – BOD meeting- 7-9pm – ASC

Thurs., Jan. 16th – Device Demo Center, Lifespan.
(from 10am to 2pm, free to all.) also, see page 7

Tues., Jan. 21st – PAC meeting, 7-9pm, ASC

SAVE THESE FUTURE DATES

Tues., Feb. 11th - BOD meeting – 7-9pm – ASC

Thurs., Feb. 20th -Device Demo Center, Lifespan

WEATHER – During the winter, the rule to follow for cancelations of meetings is: IF THE ROCHESTER CITY SCHOOL DISTRICT IS CLOSED, OUR MEETINGS ARE CANCELED. (No other notification will be made.)

Also, see page 11 info from St. Paul's Church.

Hospitality Duties for January:

Daytime Meeting – Charlie Johnstone, Carol Loftus

Evening Meeting – Barb Law, Ginger Graham

Board of Directors –Tom Corteville, John Eckhardt,
Lorin Gallistel

PAC Meeting –Dan Brooks, Lorin Gallistel,
Jennifer Hurlburt



We need your support! Rising costs are making the mailing of Newsletters to non-dues paying members difficult. Please pay your dues!

JANUARY PROGRAMS

At St. Paul's Church, East Ave. & Westminster Rd. 14607
(Enter only through the Westminster Road door.)

Tues., Jan. 7th - 10:00am - Vestry room

HOPE (Hearing Other People's Experiences) session – Joe Kozelsky, MS, abd, CCC-A (retired).

Prospective, new or long-time hearing aid users share their experiences, questions, and hearing loss journeys in an informal round table discussion facilitated by Suzanne Johnston, President, Rochester chapter. All are welcome!

Tues., Jan. 7th -Daytime Meeting -11am-1pm
Speaker begins at Noon in the Parish Hall.

What is Listening Effort? The Emotional and Mental Fatigue of Hearing - Laura Arney

Your hearing loss forces you to work hard to understand social conversations! How is it that we make sense of the words we hear? Laura Arney will present a beginners' overview of mental processes involved in hearing loss, specifically the mental effort and stresses weighing on the person with hearing loss attempting to listen to conversation. These concepts were introduced to her at the June 2019 HLAA convention in “The listening effort experience of adults with hearing loss,” a dissertation by Alison Marinelli Ph.D.

(continued on page 2)

Tuesday, Jan. 7th – Daytime Meeting - continued

Holder of a BS in biology, Laura worked as a water quality lab technician with Monroe County from 1998-2008. She has managed her hearing loss for about thirty years.

Tues., Jan. 7th – Evening Meeting–7:00-9:00 pm
Speaker begins at 8:00 pm**Hearing Other People's Experiences (HOPE)-**
Suzanne Johnston, MA, CCC/SLP

Until tonight, **HOPE** interactive discussions have been a daytime HLAA phenomenon. Tonight, Chapter President Suzanne Johnston will moderate the same “Hearing Other People’s Experiences” for chapter members attending the evening meeting.

Prospective, new, or experienced hearing aid users can share their experiences, questions, and hearing loss journeys in an informal round-table discussion. Participation is “free form” with input from hearing loss peers. It is especially valuable for newcomers to hearing loss and those adjusting to their new world of not hearing well.

Suzanne Johnston is a speech/language pathologist in private practice. She has worked with deaf and hard-of-hearing individuals throughout her career and recently began losing her own hearing. Co-founder of the Aphasia Support Group at Nazareth College, she also is a Deacon for Deaf Ministry in the Episcopal Diocese of Rochester. A long-time member and friend of HLAA-Rochester, Suzanne is the chapter President for 2019-20.

All HLAA programs are free. Our meetings feature an inductive loop hearing system and open captions. For more information, view the organization web site at hearinglossrochester.org or telephone 585 266 7890.

The Rochester Chapter is a dynamic group of individuals working together as a team. HLAA has a support network of organizations: Bethesda, MD; state organizations; and, local chapters.

LEADERS COLUMN

By Suzanne Johnston, President



This Leader’s column comes to you with **Greetings for the New Year and Good Wishes for a Peaceful and Prosperous 2020.**

Winter is upon us, and the colder days and warm homes beckon us to ‘hibernate’ and quietly reflect on these times of years past and future.

During this time HLAA-Rochester is not resting quietly, but is busy pondering where we see ourselves moving into the future. Where do we see success? What has worked well? And, maybe more importantly, what has been a challenge? Where can we improve? And so it is prudent to be thoughtful about change that needs to occur within HLAA-Rochester so that our organization can stay current, effective and relevant.

First, we need to reflect on what our chapter is doing now. Did you know that HLAA-Rochester is one of the largest and most active chapters in the U.S.? Are you aware that our organization has over 30 Standing Committees, populated by volunteer members who do all the work of our organization? These include everything from fielding phone calls; maintaining archives; selling hearing aid batteries; organizing refreshments and community events; to outreach/education into various industries in the community; to staffing our Assistive Listening Device Demo center; to creating, publishing and distributing our award-winning Newsletter; to maintaining Facebook and our award-winning Website accounts; to tracking data to advising facilities regarding Assistive Listening Systems. The list goes on. And, these committees are always welcoming new members, should you desire to help! If you would like to join the active members of our chapter, please contact Suzanne Johnston, President at sejohnston1959@gmail.com or (585)314-1807, or Art Maurer, Vice President at amaurer40@frontier.com or (585)670-0053.

(continued on page 3)

LEADERS COLUMN (continued)

Any large organization (and, at this time, we are at our highest membership number in history) supports a variety of people and groups with different interests and availability--some of HLAA-Rochester's members are extremely active, doing the work of the chapter, while others prefer to support the organization in different ways--through attending meetings, donations, etc.

So, how do we remain relevant to **all** our members? How do we continue to serve a broad and diverse community? We work to empower our members to share with us their ideas and thoughts.



By now you should have received in your mailbox a **Strategic Planning Survey** that requests your responses regarding thoughts and ideas related to HLAA-Rochester's current activities

and efforts. The survey is only as effective as the tabulation and study of responses that are provided, so our chapter is hoping that you have taken the time to **complete the survey and drop it in the mail**.

This is a valuable way for **all** our members to be involved in the work of the organization and efforts to keep it successful and relevant--without having to leave the comfort of your living room! And, during these cold days of winter in upstate NY, that's worth doing. Thank you from HLAA-Rochester chapter, and Happy New Year!



Sincere happy birthday greetings to members who will be 90 years or older! Congratulations to **Bob Edelman –January 23.**

Have a happy day and a healthy year!

SOMETHING TO THINK ABOUT...

"The time is always right to do what is right."
Martin Luther King, Jr. 1929-1968. Martin Luther King day is the third Monday in January.
(January 20, 2020)



HOPE meets at 10:00 am in the Vestry Room at St.

Paul's, first Tuesday of the month. (Hearing Other People's Experiences) January 7th.

We hope you stay for our regular Chapter Meeting on "Stress, Hearing Loss, Listening Efforts."

Save the date of February 10th for JCC Matinee Captioned Show!

By Barb Law, Special Events Chair



HLAA Theater Event at the Jewish Community Center, **Sunday, February 10th at 2 pm**, 1200 Edgewood Avenue, Rochester 14618

"The Hit Makers: The British Are Coming"

A captioned performance of an all-new show at a discounted rate of \$28!

Following the show, please join us for a light meal at Root 31 Café. The cafe's back room is reserved for HLAA from 4 pm on. Root 31 Cafe is located at 3349 Monroe Ave in Pittsford Plaza between Trader Joe's and the movie theatre.

Reservations and ticket payment are due with a check made out to Barbara Law by **January 10th**. Please send checks to:

Barb Law, 25 Harvest Road, Fairport, NY 14450.

Dinner cost is on your own.

To hold your ticket– blaw1@rochester.rr.com.

Hope to see you there!

A FUN FACT...

"If 'Candlemas Day' be stormy and black,
It carries the winter away on its back."

(from Old Farmer's Almanac)

(this is talking about Groundhog Day the first Monday in February—February 3, 2020.)

RBTL LIVE THEATRE—CAPTIONED!

All performances are **Sunday, at 1:00 pm**

Jan. 26, 2020 – Anastasia
 Feb. 23 - Jesus Christ Superstar
 March 22 - Hello Dolly
 April 26 - Cats
 June 7 - Dear Evan Hansen

Anything we add will remain up to date at this link as needed to reference: <http://www.rbtl.org/accessibility-services/>
 Tickets become available 6 weeks in advance of each show. Request seats in “open captions” viewing section. Call 222-5000; email, info@rbtl.org.

GEVA THEATRE – CAPTIONED PLAYS !

Sat. shows 2pm;
Wed. 2pm & 7:30pm
unless otherwise indicated

Sat., Jan. 18; Wed., Jan. 29 – **Slow Food**
 Sat., Feb. 22; Wed., March 18 – **ONCE**
 Sat., March 7 @ 2:30pm – **Cry It Out**
 Sat., April 4; Wed., April 22; **Looks Like Pretty**
 Sat., April 25 @ 2:30pm – **Where Did We Sit on Bus?**
 Sat., May 9; Wed., May 27 - **Vietgone**
 Call the Box Office at 232-4382. Ask for seats in the “open captions” viewing section.

CAPTIONED MOVIES AT CINEMA THEATRE

By Gaelen McCormick

All Wednesday movies at the Cinema are **open caption.** They rotate movies every week and are a LOT less expensive than the AMC and Regal cinemas. Check local listings or www.cinemarochester.com or www.captionfish.com

The Cinema Theatre is located at 957 Clinton Ave. S. (14620); 271 1785; Free parking in Dollar Tree lot across the street. Handicap parking behind the Cinema Theatre.

HAPPY NEW YEAR

JCC CenterStage – Captioned Plays!

Wed/Thurs @ 7pm; Sat/Sun @ 2pm
unless otherwise indicated

Sun., Feb. 9; Wed., Feb. 12 – **“Hit Makers—Origins of Classic Rock”**

Feb. 9 @ 2pm—Chapter special event. (see page 3)

Sun., April 12; Thurs, April 16 – **“Sweat”**

Sun., May 10; Wed., May 13 – **“Mamma Mia, musical”**

Tickets and information are available at www.jcccenterstage.org or (585) 461-2000. *Please specify “Captioned Area.”* Tickets are \$26-33 with discounts for JCC members, full-time students and season subscribers.

NTID THEATRES

PANARA THEATRE - captioned

Thur/Fri.-7:30pm; Sat.-2pm, 7:30pm
Sun.-2pm (unless otherwise indicated)

MAGIC SPELL THEATRE – captioned.

Panara Theater parking in Lot “L”
 Magic Spell parking in Lots “E” & “F”
 Cost: \$12 general public More Info:
https://www.rit.edu/cla/finearts/theatrearts/cla-ntid_18-19jointseason.

THE LITTLE THEATRE

By Scott Pukos, PR for The Little

We offer ‘open captions’ every Tuesday. Listed on our website (thelittle.org); info gets updated every Monday evening. Also, have ‘hearing amplification headphones’ and ‘personal captioning devices’ that are available for every film with closed captioning capabilities. These can be used in all theatres.

A ‘hearing loop’ (installed with the support of Hart Hearing Centers and the J. Stuart and Phyllis I. MacDonald Fund) is in Theatres 1,2,4, and 5; and soon to be in #3. For more info, go to: <https://thelittle.org/accessibility>.

CAPTIONING OF MONTHLY CHAPTER MEETINGS WILL BE CONTINUED !

Great news! Our Daytime and Evening monthly meetings will continue to be **captioned**.

The captioning is done remotely by Alternative Communication Services—it is flawless, plus the people doing the captioning are from all over the country! It's amazing to see the words almost instantly on the screen as soon as they're spoken.

We are extremely pleased that **CaptionCall** has chosen to support our chapter by underwriting the captioning at our monthly meetings.

We also owe a huge debt of thanks to **Dan Brooks, Lorin Gallistel, Charlie Johnstone, and Bruce Nelson** for overseeing the technical support needed for this service. Without their dedication in attending *all* meetings, this would not happen!

DID YOU KNOW...

In April 1968, the Civil Rights Act of 1968 was signed into law by President Lyndon B. Johnson, one week after the assassination of Martin Luther King, Jr. *(from D&C)*

HELP WANTED!

Volunteer for HLAA-Rochester Chapter
“Historian”

Job description: Obtains scrap book.

Follows In Good Health, Post, Pennysaver, any other media for stories concerning our Rochester Chapter and/or its members.

Clips stories, affixes them in scrap book.

Please contact

Suzanne Johnston, Chapter President, to volunteer. hlaa.rochester@yahoo.com
or, phone 585-266-7890

For Your Donation to HLAA:



--Phyllis & J. Stuart MacDonald Estate
--Dr. Ruth P. Oakley Estate
--Rochester Area Community Foundation
--Mary Tuckley Estate
Target Corporation - Anonymous

Donation Above Membership

Donna Blondell; Patricia Irr; Rabbi Elana Kanter-Wasserman; Bruce and Candi Nelson; Network for Good (anonymous via Facebook); Elaine Vander Brook; Angella Weber

For Donation via MacDonald Fund:

Sam Trychin

GRATEFUL THANKS TO ALL CONTRIBUTORS!
Please consider a donation when you renew your membership.

**Not yet a member of HLAA? Come join our Chapter. See what you've been missing!
Please see inside back cover page. Welcome!**

RIT NEWS: NEW APP ENHANCES MUSEUM ACCESSIBILITY FOR VISITORS

A new app developed by researchers at NTID is providing a self-guided tour platform designed to enhance accessibility for all visitors in museums. Museum visitors can use the app, MUSEAI, by inputting a number that is placed next to the artwork, which will provide them with the information about a specific artwork, including descriptions, historical facts, media (video/audio) with captions, audio descriptions and more. The app is being used for the first time nationally at Rochester's Memorial Art Gallery in a current exhibit, “De’VIA: The Manifesto Comes of Age,” which runs through February 16, 2020.

SUBJECTS OF UPCOMING MEETINGS

By Janet McKenna, MLS

Tuesday, February 4th

Daytime: “Audiologist—Carolynne Pouliot, Au.D. discusses hearing aids and hearing loss”

Evening: “Relationships”—past Chapter President, and current NYSA President, Dan Brooks, moderates a round-table discussion on how hearing loss affects everyone else we deal with.

LIKE US ON FACEBOOK !

By Jenn Hurlburt

Are you on Facebook? If so, please be our friend. We currently have **386** friends and we want more. Find us at: **Hlaa Rochester Ny**

FEATURED SPEAKER PROGRAM

Tuesday, May 12, 2020

By Elise de Papp, M.D.



Dr. Anton Porsteinsson speaking on – **“Hearing Loss and Dementia”** (topic and speaker selected by membership) to be held at The Rochester Academy of Medicine

(RAOM) 1441 East Ave., Rochester NY 14610 – Time – TBD.

This is not the first Tuesday of May. It will replace the May daytime and evening meetings.

OSHER Catalog - Winter 2020

By Janet McKenna, MLS

Smiling at OSHER members is our own

Elise de Papp, M.D., pictured on page 11 of their Winter 2020 Course Catalog. Osher's Life Long Learning Institute at RIT features classes for seniors at a campus in Henrietta with a few Friday classes held in Penfield.

Assistive Listening Systems (FM receivers) are standard in Osher classrooms with microphones passed to all speakers. Elise has been instrumental in promoting the system. She is in charge of the weekly Pfaudler Lecture Series.

HLAA New York State Association (NYSA) -

Update.

By Dan Brooks, President, NYSA



Here is the latest from the HLAA New York State Association (NYSA). This is Dan Brooks writing... As many of you have heard, our state association has been revitalized. We had our first in-person HLAA-NYSA Board of Directors meeting November 16th in the Albany area. It was a six-hour meeting and it was well attended. In total there were 13 people present at the meeting and 5 that called in remotely, including our captionist. All the committees provided reports, and we are off to a great start!

Here is a look at what was discussed...the need for a state agency for Deaf and hard-of- hearing people; how we can help facilitate more and new chapters within our state; talks of getting our own website online; and the next HLAA State Conference! So kid you not, this was just a glimpse of everything that was discussed and goals that were set. Goals that will require many to come together to make them happen.

Also by now you should have heard the announcement made by Barbara Kelley, our HLAA Executive Director, that it is official: The HLAA NYSA has been revived. Our slate of board members and officers was introduced. If you did not receive this information, it may be because you are not a member of HLAA. In case you were not aware, by joining HLAA (\$45 individual) and living in New York State, you are automatically a member of HLAA-NYSA. (please see form in back of this Newsletter to join HLAA national)

So please consider joining or renewing your membership with HLAA and in doing so, you are helping HLAA-NYSA as well. We can use all the support we can get so we are able to do all that we have set out to do! If you have questions or are thinking about joining our efforts, please feel free to reach out to me at: hlaa.newyorkstate@gmail.com or dbrooks.hlaa.roc@gmail.com

ASSISTIVE LISTENING DEVICE DEMO CENTER

By Charlie Johnstone



The demo center sessions continue to be a success thanks to the enthusiastic efforts by our regular,

long-term volunteers (**Dan Brooks, Lorin Gallistel, Stan and Michelle Gross, Eric Matson, Sue Miller and myself**).

Visitors are very appreciative of the attention and help they receive. There are few places where people with a hearing loss can go to get instant help and quality, free information! Lifespan's generosity in so many ways, combined with the hard work and contribution of so many volunteers really makes a difference!

The types of devices represented during the demo sessions include signaling-alerting devices, captioned and amplified telephones and personal assistive listening devices [with an emphasis on TV listening and coping with noisy environments]. Several new, lower cost devices and smart phone apps are being shown. In addition, an interactive, computer-based "Virtual Demo Center" is being pilot tested.

The Device Demo Center is open the 3rd Thursday of each month (except July and August). The next demo session at Lifespan, 1900 S. Clinton Ave. (Tops plaza) 14618 is Thursday, January 16th, from 10am to 2pm. Free. All are welcome!

We Welcome All Donations

Please make your check payable to: HLAA-Rochester
HLAA is a 501©(3) organization.

Mail to: Ms. Joan Kohler
15 Pickett Lane
Hilton, NY 14468

Be sure to designate:

This donation is: In Memory of; or, In Honor of
or, Birthday congratulations. And who to send the Acknowledgment to.

With sincere thanks for donating to our Chapter!

WEBSITES OF INTEREST

Our award-winning Chapter website is:

<http://www.hearinglossrochester.org>, and

Michelle Gross is our Web Master.

HLAA National website is www.hearingloss.org.

This award-winning Newsletter of the Rochester Chapter of HLAA is published monthly except for July and August.

Editor and Publisher.....Ginger Graham
Computer Consultant,

Webmaster, and Writer.....Michelle Gross
News Releases, and Writer.....Janet McKenna
Photographers.....Art Maurer, Al Suffredini

We need your support! Rising costs are making the mailing of Newsletters to non-dues paying members difficult. Please pay your dues! Only \$10. (Please see form inside back cover.)



THE EFFECTS OF HEARING LOSS ON SPEECH

Everyone with hearing loss knows how it can affect communication, making it difficult to carry on a conversation and understand those around you. But did you know that it can also affect your ability to communicate by impairing your ability to produce and control your speech?

The intimate link between speaking and hearing has long been acknowledged by both individuals with hearing loss and the medical community, but it has not received the same attention given to our ability to perceive and understand sounds. Babies born with hearing loss have much more difficulty learning normal speech and language and often need extensive speech therapy. Even then, many end up with speech that sounds abnormal and difficult to understand by those not used to communicating with them, since it lacks fine precision and contrasts between different consonants and vowels.

(continued on page 10)



Happy Holidays!

IF YOU MOVE, or are a "SNOWBIRD!"

Please don't forget to notify **Henry J. Adler, Ph.D.**, Univ. of Buffalo, 137-L Cary Hall, 3435 Main St., Buffalo NY 14214; or – hjadler@aol.com, even if your change of address is a temporary one.

HLAA is charged for each piece of returned mail, which the Post Office will not forward. When you return, we will resume sending to your local address.

We need your support! Rising costs are making the mailing of Newsletters to non-dues paying members difficult. Please pay your dues! Only \$10. Thanks so much. (Please see form inside back cover.)



BIRTHDAYS – 90 YEARS AND OVER...

Everyone: please let me know if you're one of our special Chapter members who will reach the spectacular age of 90 years, or more. If you agree, we'd like to announce it in our Newsletter. It is important to let me know right away as our Newsletters are written a month ahead. Thanks, Ginger

ggraham859@gmail.com; or, (585) 671-2683



Flu Shots – The CDC recommends getting your flu shot now. Because flu is contagious 1-2 days before symptoms appear, it can be spread before we know we're infected. For more info, go to: www.cdc.gov/flu.

CDC reports some people can be contagious up to a full day before they become symptomatic and up to a full week afterward.

YOUNG ADULT GROUP

Our chapter has a Young Adult group and welcomes those with or without hearing loss to participate.

Please go to our website for details -

www.hearinglossrochester.org, or contact Jennifer Hurlburt, at jennhurlburt@gmail.com



HOPE Session 11/5/2019

By Joe Kozelsky, *abd, MS,*
CCC-A (retired)

This was another fun session. We had 12 people, with one new person, and it was a special treat for me because one of my former patients (who lives in Skaneateles and who is looking at replacing her hearing aids) made the trip to Rochester to attend this session.

During our discussion, the issue of **hearing aid cost** came up and one of our regular members made the point that hearing aids aren't like other ear-level listening devices. Instead, they are miniature computers and do a LOT more than just present sounds louder to the ear. This is because unlike other ear-level devices, they actually modify the acoustic signal in REAL-TIME; whereas, other ear-level devices are passive and serve only to amplify already listener-idealized acoustic signals.

Everyone has seen examples of sound recording studios which are designed to prevent the intrusion of unwanted sounds, and where multiple people are involved to make sure that the signals are fully optimized for loudness, pitch, comfort, and overall sound quality before they are presented for recording or for over-the-air presentation. So, everything heard through other ear-level devices has been fully optimized before it is presented to the ear.

Hearing aids don't have that advantage. They have to do all of the optimization of the auditory signals as they occur at the ear, and that necessarily adds cost.

Newsletter Deadline

Tuesday, December 31st
(for the February 2020 Newsletter)

Email: ggraham859@gmail.com

INTERESTING NUMBERS...

Ben Franklin was born on Jan. 17, 1706 and was one of 17 children; he moved to Philadelphia when he was 17; and died on April 17, 1790.

“MY STORY –A Personal History of Hearing Loss*By John Eckhardt, Ph.D.*

My hearing loss story is similar to those of many others. When I began to experience hearing loss in my mid-fifties it was not surprising nor unexpected. I had seen it happen to my father and my grandfather. What I was not prepared for was the emotional

impact that would accompany the increasing severity of the HL and the ways that it would change my life.

In the beginning, my hearing loss was mild and was, essentially, a minor irritant. I would miss words occasionally, but rarely was it a problem. That didn't last long and soon I purchased my first hearing aids. The hearing aids were helpful for a time as the amplification they provided allowed me to continue my life's activities. My hearing continued to deteriorate to severe and profound levels. By this time, I was on my third set of hearing aids and they were no longer helping me communicate. Approximately ten years after I first became aware of my hearing loss, I left my faculty position at the University of Rochester. (I had taken a position at UR following more than thirty years in public education--serving as superintendent of schools in Canandaigua and Brighton.) This ended a 45-year association with the University as I had been an undergraduate and a graduate student there.

As my hearing continued to deteriorate, my ability to communicate with family and friends began to disappear, just as it had with students and colleagues. The emotional effects and frustration were devastating. I began to retreat from those around me. I avoided situations that required any level of communication. Many were activities that I had previously enjoyed--golf or dinners with long-time friends, presentations and seminars, even our winters in Florida. I avoided anything that required me to hear and possibly communicate. This was difficult not only for me, but also for those around me. No one was more impacted by this than my wife, Joan. She lived with these circumstances for

several years and she was incredibly supportive and helpful. Fortunately, my children were grown.

During these years, I tried every hearing aid and assistive device I could find. I met with several audiologists and contacted several universities in hope of finding a magic bullet. I was referred to URMH for a medical evaluation because I was exhibiting some signs of an acoustic neuroma. CT scans were negative and I was referred to Dr. Christina Bauer, an audiologist in the Otolaryngology department. Christina suggested that I consider a cochlear implant. I knew little about cochlear implants and was resistant to the idea. Ultimately, I decided to explore them and read as much research as I could find. I also contacted medical centers that specialized in CI's to learn what the most likely outcome for me was. In spite of these efforts, I never felt confident that I had a reasonable idea of what a cochlear implant would do for me.

Fortunately, I met a local implant recipient. She graciously spent time answering my questions and told me that the surgeon who performed her implant surgery, Dr. John Wayman, had been a great help and resource for her. I scheduled an appointment and found that all I had been told about him was clearly evident. I left the office confident that I would soon get an implant.

I received my CI in May, 2015. The surgery and recovery were challenging, but the results have been miraculous. I'm back to doing the things that I enjoyed but avoided. I can communicate effectively in most situations and the frustration and anger that I experienced during my most difficult times are gone. I'm especially grateful to the people who helped me through this. Now, through my involvement with HLAA, I hope I can continue to help others on their journey.

SOMETHING TO THINK ABOUT...

"In the depths of winter, I finally learned that within me there lay an invincible summer." *Albert Camus*
(from *Old Farmer's Almanac*)

EFFECTS OF HEARING LOSS ON SPEECH

(continued from page 7)

When someone is born hearing but loses hearing later in life, there are also changes in both speech and voice, though these are subtler than in children.

Interestingly, the important role of hearing in speech is not limited to those with hearing loss. Normally hearing individuals are constantly, and unconsciously, listening to themselves while they talk in order to correct any errors. This is why people tend to speak loudly or shout in a noisy room. They cannot hear themselves, something we call feedback, and speak louder in order to do so.

Sometimes you even change the pitch of your voice, depending on how you hear yourself. Also, when the feedback of your speech is delayed (think on a bad speaker phone connection), you can get tripped up and start making errors. Some researchers even think this may be one cause of stuttering! All this is mostly reflexive—you do not even know that you are doing it.

What does this mean for those with hearing loss? It is clear that this loss of control has real implications for making vocal communication difficult in hearing loss. Unfortunately, the technologies we employ to help hearing loss are not designed with this in mind. While giving someone with profound hearing loss a Cochlear Implant can substantially improve their ability to understand others, the effects on their ability to control their own speech and voice are more limited and quite variable. We recently took a look at all the papers that have been written on Cochlear Implants and the control of speech/voice, and there is surprisingly not much. Certainly, these devices help, but never quite to the level of those with normal hearing

Here at Penn Medicine, we have ongoing research on how well patients with Cochlear Implants are able to use their implant to control their voice on a moment-to-moment basis, and how this is affected by quality of the hearing they get from their implant. We are also looking at how someone with hearing loss learns to control their speech and voice when their hearing condition is modified with a hearing

aid or CI. We are even investigating how the brain allows us to do this complicated control of our speech (and why our voicemail doesn't sound quite the same as what we think our voice sounds like).

We are very excited about this research and how it may allow us to round out our approach to communication difficulty in hearing loss.

Steven J. Eliades, M.D., Ph.D.

Assistant Professor

Department of Otorhinolaryngology-Head and Neck Surgery

University of Pennsylvania Health System

(from “Hear Say” PA Newsletter, Fall 2019))

CLOSED CAPTIONING ON TV'S

By Ginger Graham

The original bill for requiring CC to be enabled on televisions in public venues initially was directed to the City. It went to the NY state Senate in 2015 but reappeared and was signed by Governor Cuomo September 13, 2019. Effective July 1, 2020, the County will also be required to have captioning on public TV's. For more information, go to:

<https://legislation.nysenate.gov/pdf/bills/2019/S1650>

Thanks to **Bruce Nelson** for researching this material for our members.

HLAA Chapter meetings are communication accessible, featuring Real-time Captioning, and the room is equipped with a hearing loop! Please don't stay away because you think you won't be able to hear and understand well. What you find out could change your life!

HLAA CONVENTION – June 18-21

New Orleans, Louisiana

Early bird registration is now open, and available until March 2nd. Reduced rates. For details, go to: www.hearingloss.org.

VENUES WITH ALS OR CAPTIONING

By Tim Whitcher

Have you seen a movie or a show that has an Assistive Listening System or Captioning system and would like to share your experience with your fellow members? Did your church or synagogue install or upgrade such a system, and you'd like to make that known?

Please contact Tim Whitcher at hlaa.rochester@yahoo.com with the info that you'd like to share. (Please mark your email to Tim's attention.) Likewise, if you have a question regarding such a venue, please contact Tim.



By Nancy Meyer

Did you know that our chapter has a Lending Library? There are several books and DVDs available for members to sign out for a month at a time. They are on display at the front of our meeting room. Sign out one (or more), and return them at the next month's chapter meeting.

Members have donated books; you can too! Please bring them to a meeting. Right now, we have available to borrow:

Gael Hannan – "The Way I Hear It"
Katherine Boughton – "Living Better w/Hearing Loss"
Monique Hammond – "What Did You Say?"
Art Maurer – "Twisted Vines;" also, "Frackin' Lives"; and more to choose from!



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ANOTHER GOOD MAGAZINE...

By Ginger Graham; suggested by Fred Altrieth

In addition to our own *Hearing Life* magazine, another one with excellent articles is *Hearing Health*, published four times annually. Some of the topics from the Fall 2019 magazine:

- Have a hearing loss, in the hospital
- Hearing loss and dementia
- BAHA –brought me back to life
- Estrogen's role in hearing loss
- Veterans: Reviewing Tinnitus research; defective ear plugs; learning to love my hearing aids.

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3. *The wind chill is at or below -20 degrees.*

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SAVE THESE DATES:

- May 12, for FEATURED SPEAKER PROGRAM
- May 19, for Chapter's Annual Dinner
- August 9, Picnic

A BIT OF HISTORY...

In January 1993, the Martin Luther King, Jr., holiday was observed in all 50 states for the first time.



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**HLAA Membership
Information**

Hearing Loss Association
 (HLAA) Rochester Chapter,
 Inc., a tax exempt and
 volunteer group, is a chapter of
 a national, nonprofit,
 nonsectarian, educational
 organization devoted to the
 welfare and interests of those
 who cannot hear well. We meet
 the first Tuesday of the month
 from October through June at
 St. Paul's Episcopal Church,
 East Ave. (September is 2nd
 Tuesday.) While our primary
 focus is directed toward people
 with hearing loss, we welcome
 everyone to our chapter
 meetings whatever their
 hearing ability.

For more information, Call

585 266 7890

Professional Advisors**2018 – 2020**

Kathy Foster
Emily Krohn
Ralph Meranto
Nicholas Sprague

2019 – 2021

Nathan Herring
Carolynne Pouliot
Hope Scheda
Nicholas Stefanovic

Consultants

Medical - Paul Dutcher, M.D.
Technical - Charles Johnstone
Legal - James Vazzana, Esq.

^^

Newsletter

*Newsletter deadline: first day of the
 month preceding the issue month.*

Send articles to:

*Ginger Graham, 859 Meadow Ridge Lane
 Webster, NY 14580*

ggraham859@gmail.com

MEMBERSHIP FORM – HLAA-ROCHESTER CHAPTER

July 1, 2019 – June 30, 2020

☐ I want to join as a first-time member ☐ I want to renew

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If You're New, This is for You.

More than 48 million people in the US have a hearing loss, which can hinder daily communication. By age 65, one in three Americans has a hearing loss. This invisible condition affects the quality of life of the individuals with hearing loss as well as family, friends, co-workers and everyone with whom they interact. HLAA believes people with hearing loss can participate successfully in today's world.

Founded in 1979, the mission of HLAA is to open the world of communication to people with hearing loss through information, education, support and advocacy.

HLAA is the nation's foremost membership and advocacy organization for people with hearing loss. HLAA publishes the bimonthly Hearing Life Magazine, holds annual conventions, a Walk4Hearing, and more. Check out: <http://www.hearinglossrochester.org>.

The Rochester Chapter, started in 1983, is a dynamic group of individuals working together as a team. To join, please see inside back page. HLAA has a support network of organizations—Bethesda, MD; State organizations; and, local Chapters. Welcome!

Meetings are hearing accessible

We meet in St. Paul's Episcopal Church, East Ave. and Westminster Rd., across from the George Eastman Museum. Parking is available at the George Eastman Museum, if needed.

All meetings are audio looped and captioned. Interpreters are available on request *for evening meetings only*-- contact Linda Siple, 585 288 6744, or at lasnss@rit.edu, at least a week in advance.
(This phone number is only to request an Interpreter.)

Entrance to the meeting room is via the Westminster Rd. door, down the corridor to the end, into the large Parish Hall room.

Everyone, with or without a hearing loss, is welcome!