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May 2017

### MAY Calendar

#### Tuesday, May 2<sup>nd</sup>

**10:15 am – HOPE Session–Vestry Room**

11:00 am - Refreshments/Social Time

11:30 am – Announcements/Business Meeting

12 Noon – 1 pm – Program Speaker

7:00 pm – Refreshments/Social Time

7:30 pm – Announcements/Business Meeting

8:00 pm – 9 pm – Program Speaker

Tues., May 9<sup>th</sup> - BOD meeting, 7-9pm, ASC

Tues., May 16<sup>th</sup> –“Featured Speaker”– see page 3

Tues., May 23<sup>rd</sup> – Annual Dinner”- see page 11

#### SAVE THESE FUTURE DATES

June 22 – 25 – Convention, SLC, - see page 7

Tues., June 27<sup>th</sup> – Program Planning meetings -  
see page 3

**WELCOME ALL NEWCOMERS TO HLAA!**



### MAY PROGRAMS

(At St. Paul’s Church, East Ave. & Westminster Rd. 14607

**Enter only thru Westminster Rd. door.**

**Tues., May 2<sup>nd</sup> – 10:15–11am; Vestry room**

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

Retired audiologist and hearing aid user **Joe Kozelsky** moderates a question and answer group for people considering hearing aids and those using them. Join us and share your hearing loss journey and learn from others. (see page 5)

**Tuesday, May 2<sup>nd</sup> - Daytime Meeting—  
11:00am Program begins at noon**

**Audiology in Ethiopia: Perspectives on  
Cultural and Clinical Experiences –**  
*Catherine Clark, Au.D.*

Dr. Catherine Clark is the volunteer audiological consultant for programs established by Global Visions Empowerment in Bahir Dar, Ethiopia. She initially traveled there in 2014 with Nazareth College students to participate in a service learning project established for deaf and hard-of-hearing Ethiopians, most of whom had never had a hearing test. In 2015 Dr. Clark established an Audiological Assessment and Intervention

*(continued on page 2)*

#### **Hospitality Duties for May:**

Daytime Meeting –Kathy Curre, Janet McKenna,  
Al Suffredini

Featured Speaker – Margaret Cochran, Barb Law,  
Carol Loftus

Board of Directors –Barb Law, Cathy Lee,  
Carol Loftus

***Please sign up to help when the “Refreshment Sheet”  
goes around!***

**Tuesday, May 2<sup>nd</sup> – Daytime** (continued)

Center with the assistance of Global Visions Empowerment, audiology suppliers and Ethiopian partners. To date, over a hundred Ethiopians have received audiological services, including hearing aids for children and adults. The presentation will describe challenges and successes involved in creating a sustainable audiology program there. Images and products developed by the Ethiopians will be shared.

Dr. Clark has served for the past thirty years as an Associate Professor, Audiologist and Coordinator of the Cochlear Implant Program at the NTID Dept. of Communication Studies and Services. She provides speech reading and auditory training, performs hearing evaluations, hearing aid fittings and services related to cochlear implants and teaches an interpersonal relationships course.

The recipient of many awards, Dr. Clark was honored with the 2016 Oticon Focus on People Award in the Practitioner category. The award celebrates individuals eliminating negative stereotypes of deaf or hard-of-hearing people.

**Tuesday, May 2<sup>nd</sup> - Evening Meeting--****\*\*THERE WILL BE NO EVENING PROGRAM\*\***

Please come to the Tuesday, May 16<sup>th</sup>, Featured Speaker Program, with Dr. D. Tucci, at the First Unitarian Church on Winton Road. (see page 3)

*HLAA-Rochester Chapter welcomes all community members with an interest in hearing loss.*

*HLAA-Rochester chapter meetings are held in the Parish Hall at St. Paul's Episcopal Church, East Avenue at Westminster Road, across from the George Eastman House Museum. All programs are audiolooped and **captioned**. Those needing a sign language interpreter for an evening meeting should contact*

*Linda Siple at 585 288 6744, a week in advance. (Please note, this phone is only for those needing an interpreter.)*

*The Rochester Chapter is a dynamic group of individuals working together as a team. To join, see inside last page. HLAA has a support network of organizations-Bethesda, MD; State organizations; and local Chapters. Welcome!*

**RESEARCH STUDY WANTS VOLUNTEERS!**

*By Jennifer Forquer, Research Program Coordinator*

**Mechanisms of Health Literacy and Information Accessibility in the Deaf and Hard-of-Hearing Study**

Mission: To understand differences in attitudes, knowledge, and skills as they relate to health information, knowledge and access among deaf, hard of hearing, and hearing individuals with the goal of improving access to health information for all. Goals:

- Expand the evidence base on visual learning and its relevance to health information
- Eliminate existing disparities in health information access and knowledge
- Empower deaf, hard of hearing, and hearing people regardless of their health literacy, to access reliable health information

**We need you!** Our study is currently collecting data from interviews with deaf, hard-of-hearing and hearing participants. The interviews take approximately 2 hours on RIT campus (Rosica Hall-room 2160). We will provide directions and a parking pass.

Please contact through FB messenger or go to the website below and sign up. You will be paid \$40.00 for up to 2 hours of your time! Go to: <http://www.healthinfolab.com/> or, [jlfcc@rit.edu](mailto:jlfcc@rit.edu)

**“COCHLEAR IMPLANT GROUP” MEETING**

*By Ginger Graham*

We had a terrific meeting April 4<sup>th</sup>, after the Chapter meeting, with 12 people in attendance. Four were new and possible candidates for an implant.

The seasoned members were eager to share their experiences, and encouraged the new folks to contact any of us for a one-on-one session. Topics covered: advantages of 2 implants; insurance; warranty; how the magnet works; batteries; remote control; mapping after surgery, and more.

Our next meeting will be in October. Watch our Newsletters for details. We hope to see you then.

## FEATURED SPEAKER PROGRAM

By *Elise de Papp, M.D.; and, Janet McKenna*



Tuesday, May 16, 2017

**Dr. Debara Tucci, M.D., MS,**  
MBA; Professor of  
Otolaryngology, Head and Neck  
Surgery, Duke University

First Unitarian Church,  
220 Winton Rd. South, Rochester NY 14610 -  
doors open 5:30 pm; program at 6:30pm

### “Reframing Advocacy for Treatment of Hearing Loss in Adults: A Public Health Approach”

Dr. Debara Tucci, HLA A Rochester's 2017 Featured Speaker, was a panelist for the report on "Hearing Health Care for Adults" issued by the National Academies of Sciences, Engineering and Medicine in June 2016. At Duke University she maintains a clinical/surgical practice in otology, neurotology and skull base surgery along with conducting clinical research. Prior to medical school she trained and worked as an audiologist.

She is co-principal investigator on a National Institutes of Health grant focused on establishing a national network of research sites to conduct clinical research in hearing and balance disorders. As well, she is principal investigator of a grant to study health care policy related to hearing health care in adults.

Dr. Tucci has served as President of the American Neurotology Society, Association for Research in Otolaryngology, and recently, President of the American Otological Society.

The First Unitarian Church has ample free parking. The building is accessible with an induction hearing loop and open captions. An ASL interpreter will also be provided.

Light refreshments at 5:30pm will precede Dr. Tucci's talk. The program is free and anyone interested in hearing loss is welcome.



## SAVE THE DATE!

### PLANNING THE PROGRAMS FOR YOUR CHAPTER MEETINGS

Are you tired of “the same old subjects” at our Chapter meetings? We hope not!! But we do need your input and **new ideas for programs!** Please plan to attend either the Daytime Program Planning meeting held by Sue Miller, or, the Evening Planning meeting held by Barb Law, to give them your ideas for possible topics for the new season from September, 2017, to June, 2018.

#### Daytime meetings planning session:

**Tues., June 27<sup>th</sup>, at 9:30am – coffee & conversation; then, discussion 10:00-Noon – Sue’s home, 16 Buckthorn Run, Victor.**

#### Evening meetings planning session:

**Tues., June 27<sup>th</sup>, at 6:00 – 9pm with Barb Law, in 1<sup>st</sup> floor Conf. room, Al Sigl Center; light snacks.** Both meetings are on the same day.

**RSVP:** Please email (or, call) either Sue or Barb and let them know you’re attending. We appreciate an RSVP for seating and food! Hope to see you at one or both of the meetings! We’re eager for your suggestions!

Barb Law: [Blaw1@rochester.rr.com](mailto:Blaw1@rochester.rr.com);  
(585) 381-8640

Sue Miller: [SusanLeeMiller39@cs.com](mailto:SusanLeeMiller39@cs.com);  
(585) 924-8933

## 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](mailto: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.

**RBTL LIVE THEATRE—CAPTIONED!**

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

“Cabaret” – May 7<sup>th</sup>

Tickets become available 6 weeks in advance of each show. Request seats in “open captions” viewing section. Call 222-5000; email, [info@rbtl.org](mailto:info@rbtl.org).

**GEVA THEATRE – CAPTIONED PLAYS !**

SAT. shows 2pm; WED. 2pm & 7:30pm  
unless otherwise indicated

“Other Than Honorable” - Sat. April 29; Wed. May 17

“Million Dollar Quartet” - Sat. June 3; Wed. June 21

Call the Box Office at 232-4382. Ask for seats in the “open captions” viewing section.

**Newsletter Deadline**

**SUNDAY, APRIL 30<sup>TH</sup>**  
(for the June Newsletter)  
Email: [ggraham859@gmail.com](mailto:ggraham859@gmail.com)

**MEMORIAL DAY**

*By Anna Gilmore Hall*



Memorial Day honors those who died serving the U.S. military. It is traditional to fly the American flag at half-mast.

Memorial Day originated after the Civil War to honor both the Union and Confederate soldiers who died in the war. The holiday was extended by the 20th century to include all American soldiers. Memorial Day is formally known as Decoration Day. Memorial Day is sometimes confused with Veteran's Day which is in November, which celebrates the service of all U.S. military veterans.

**JCC CenterStage – Captioned Plays!**

*By Marc Cataldi, JCC*

**Wed/Thurs @ 7pm; Sat/Sun @ 2pm**



Titanic, the Musical – Sun., May 14

“Bring It On” – the musical

Sun., July 16; Wed., July 19

“Cooking with the Calamari Sisters”

Sun., Oct. 15; Wed., Oct. 18

Thurs., Oct. 19; Sat., Oct. 21

“First Date” – Broadway Musical Comedy

Sun., Dec. 10; Thurs., Dec. 14; Sat., Dec. 16

“The Hit Makers: And the Beat Goes On”

Sun., Feb. 11; Thurs., Feb. 15; Sat., Feb. 17

“Buyer & Cellar”

Sun., March 18; Thurs., March 22

“Bridges of Madison County” – the musical

Sun., May 13; Thurs., May 17; Sat., May 19

Tickets and information are available at [www.jcccenterstage.org](http://www.jcccenterstage.org) or (585) 461-2000. Please specify “Captioned Area.” Tickets are \$26-29 with discounts for JCC members, full time students and season subscribers.



For Your Donation to HLAA:

- Phyllis & J. Stuart MacDonald Estate
- Dr. Ruth P. Oakley Estate
- Rochester Area Community Foundation
- Mary Tuckley Estate
- United Way Donors
- 2016 WALK Silent Auction

Thanks to all who have renewed their membership.

If you haven't yet, please consider a donation when you renew your membership. Thanks so much!

**IF YOU MOVE, or are a “SNOWBIRD!”**

Please don't forget to notify **Cathy Lee**, at 22 Erie Manor Lane, apt.#6, Henrietta, NY 14467, or, via email at, [cathydisalvolee@gmail.com](mailto:cathydisalvolee@gmail.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.

## ADULT MUSICIANS WITH HEARING LOSS

By Jerry Bergman, President, HLAA NYS Association  
(submitted by Sue Miller)

Our friends who inspire us with music-making despite hearing loss will hold their second conference for adults with hearing loss which will be held July 13-16 at Kean University in NJ. This conference will be of interest to individuals who enjoy playing music despite the challenges that hearing loss brings. There will be opportunities to develop ensemble skills and listening skills with the assistance of hearing loop technology. Saturday afternoon, July 15, will also feature captioned presentations on the challenges of making music with a hearing loss and a viewing of the documentary, *Lost and Sound*. For more information visit the [AAMHL conference website](http://AAMHLconferencewebsite.com).

Contact Person: Wendy Cheng  
Nonprofit Name: Association of Adult Musicians with Hearing Loss (AAMHL)  
Email Address: [info@musicianswithhearingloss.org](mailto:info@musicianswithhearingloss.org)  
Web site address:  
<https://musicianswithhearingloss.org>

### 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. The service cost is \$3,000 a year and it is being paid by CaptionCall. CaptionCall has been a blessing in providing true access for everyone in our chapter... We thank you!

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



## HOPE REVIEW

By Joe Kozelsky, abd, MS,  
CCC/A (retired)

We had 12 people at the March 17<sup>th</sup> session--several new individuals, several repeat visitors and several regulars. As always, the questions and issues were very interesting ranging from comments about the relevance and validity of current audiologic test procedures, candidacy for CIs, best type/style of hearing aids, and, paraphrasing: "Why can't they do a better job with hearing in noise – after all they can send a man to the moon?" (What a great comment!). Hopefully, between myself and the various participants we were able to provide some useful answers to these questions.

Perhaps the most common of all questions is the one about where to go to get new hearing aids. I indicate that I cannot recommend a particular provider or providers. Instead, I provide a set of guidelines for getting hearing aids and suggest that the best thing to do is to "ask around." Then I go on to say that the people at HLAA are about the best people to ask where they got their hearing aids. So, if someone asks about where you got your hearing aids and how you like them, perhaps they've been to a HOPE session.

### 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 two months ahead. Thanks, Ginger  
[ggraham859@gmail.com](mailto:ggraham859@gmail.com); or, (585) 671-2683



## MOTHER'S DAY

(from the Old Farmer's Almanac)

After her mother died in 1905, Miss Anna Jarvis campaigned for a national day to honor all mothers. On May 10, 1908, a Mother's Day service was held at a church in Grafton, West Virginia. In 1914, Mother's Day was declared an annual national holiday on the second Sunday in May. Love to all Mothers!

**LIKE US ON FACEBOOK !***By Jenn Hurlburt*

Are you on Facebook? If so, please be our friend.  
We currently have **314** friends and we want more.  
Find us at: **Hlaa Rochester Ny**

**WEBSITES OF INTEREST**

Our award-winning Chapter website is:

[www.hlaa-rochester-ny.org](http://www.hlaa-rochester-ny.org). **Michelle Gross** is our Web Master.

HAAA National website is [www.hearingloss.org](http://www.hearingloss.org).

*(submitted by Janet McKenna)*

The HAAA website <http://www.hearingloss.org> has links to a remarkable article in its News section of 3-01-17. Calderone, Julia "Hearing Loss: No More Suffering in Silence?" *Consumer Reports* Feb. 02, 2017-- Or -- CR subscribers can read it there. It is very thorough and unbiased, dealing with obtaining hearing aids, different kinds, hearing loss, reasons for people's denial of hearing loss, etc. Only subscribers can see direct comparisons of different brands.

*(submitted by Karen Hubbard)*

MRI Safety and Cochlear Implants (MedEl)

<http://www.medel.com/us/cochlear-implants-mri-safety>.

*(submitted by Tim Whitcher)*

**Hearing Loops:** - Juliette Sterkens

<https://loopwisconsin.wordpress.com/2017/03/18/who-decides-about-hearing-loops/>

*(submitted by Suzanne Johnston)*

A simple study, which is predictable but makes a good case for communication/speech training for those who work in the public arena with those with hearing loss.

[http://aja.pubs.asha.org/article.aspx?articleid=2598236&utm\\_source=asha&utm\\_campaign=AJA&cmp=1&utm\\_medium=newsletter](http://aja.pubs.asha.org/article.aspx?articleid=2598236&utm_source=asha&utm_campaign=AJA&cmp=1&utm_medium=newsletter) Also, [www.goo.gl/DzUrmY](http://www.goo.gl/DzUrmY).

**HELP HAAA VIA THE UNITED WAY**

We continue to be a United Way "Donor Designated Option" choice. We are not a direct United Way agency and do not receive any funding from their general campaign. Therefore, to donate to HAAA through the United Way, we ask you to consider donating to us through the "Designated Option" on your gift card.

**Our United Way number is 2425.**



Your past support is deeply appreciated. Alas, even though the local chapter is a totally volunteer organization, there are still costs such as printing, postage, phones, and technical items. Many thanks!

This award-winning Newsletter of the Rochester Chapter of HAAA 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

**DONATING HEARING AIDS TO THE LIONS CLUB***By Michelle Gross*

If you have used hearing aids to donate, please address the package to:

John McNamara, Au.D., Ontario Hearing  
2210 Monroe Ave.. Rochester, NY 14618  
Put on the lower left corner of the package:  
"Finger Lakes Region Lions Club"

(Cleaning tools, cases, most accessories, etc. have virtually no value and are discarded.) Aids that are usable are cleaned and checked and made ready for sending to the Lions Club for qualified recipients.

You can obtain a receipt for your donation (for tax purposes) but you must request it. And, thanks for considering donating your used aids.



**Little America Hotel,**  
500 South Main Street,  
Salt Lake City, Utah 84101

**Tower Rooms • \$179;**  
**Garden Rooms • \$159 +tax**

**Reservations must be received by May 30th.**

Reference that you are with the **HLAA2017 group.**  
Visit <http://bit.ly/LittleAmericaSL>; 800-437-5288.

#### **RADISSON HOTEL-**

<http://bit.ly/RadissonSL>; 1-800- 967-9033

#### **Register Online or Offline**

Increased rates will begin April 1 and continue through May 31 when pre-convention registration closes. On-site registration will be available as well.

**Online** – login to the [HLAA Online Portal](#) and select Convention Registration on the left menu (if you don't have a login yet, go to [New User Registration](#).)

**Offline** – complete the [Early-bird Registration Form](#) and mail, fax or email the form to us. We will mail you a confirmation letter.

#### **Veterans**

##### **(Free Registration for 1st Timers).**

Those veterans wishing to attend should complete the “Veterans Registration Form” which can be obtained on the national HLAA website at: <http://hearingloss.org/content/registratiion>. In the middle of this web page is all the info about the benefit and a link to download the required form.

*(Link details provided by Michelle Gross, Rochester Chapter Web Master.)*

**Delta Air Lines** - Use Meeting Code **NMPE4** when booking to Salt Lake City [delta.com/meetings](http://delta.com/meetings), or when you call Delta Meeting Reservations at 800-328-1111. The discount of up to 10% (depending on whether you book First Class, Economy, etc.) will be applied to your fare.

Rochester members planning to attend, please go to our website: [www.hlaa-rochester-ny.org](http://www.hlaa-rochester-ny.org) for the form to fill out to receive “Reimbursement for Convention.”

#### **Subjects of June 6<sup>th</sup> Chapter Meetings:**

**Daytime** – “Ask the Audiologists” – Drs. Christine Stein, and, Christy Hobson

**Evening** – “Hands on Listening Devices Demo” – Dan Brooks, and, Charlie Johnstone

#### **OVER-THE-COUNTER HEARING AIDS ARE A HOT TOPIC!**

*By Ginger Graham (excerpt from TWIB, Barbara Kelley)*

HLAA Executive Director Barbara Kelley was interviewed recently. An article, “Hearing Aids: The FDA's Latest Mission for Digital Health,” focuses on the possibility that the FDA will create a new class of over-the-counter hearing aids. HLAA is in full support of this measure. Barbara was interviewed along with a representative from the Hearing Industries Association, an organization that represents hearing aid manufacturers and that opposes the idea of over-the-counter hearing aids.

In December 2016, Senators Elizabeth Warren (D-Mass.) and Chuck Grassley (R-Iowa) introduced the [Over-the-Counter Hearing Aid Act of 2016](#), which would require the FDA to create this new class of hearing aids. It is anticipated that the bill will be reintroduced to Congress very soon.

People are contacting national HLAA at an unprecedented rate to comment about this, so stay tuned as this hotly-debated issue develops!

(Note: the full article is available on [politicopro.com](http://politicopro.com), a subscription-based news service.)

#### **It's a Call to Action! Join HLAA in Supporting the Over-the-Counter Hearing Aid Act of 2017**

On March 21, U.S. Senators Elizabeth Warren (D-Mass.), Chuck Grassley (R-Iowa), Maggie Hassan (D-N.H.), and Johnny Isakson (R-Ga.), [reintroduced legislation](#) (S. 670) to make hearing aids for those with mild-to-moderate hearing loss available over the counter (OTC). A companion bill (HR 1652) led by Representatives Joe Kennedy III (D-Mass.) and Marsha Blackburn (R-Tenn.) was also introduced in the House.

*(continued on page 8)*

## OVER-THE-COUNTER AIDS *(continued)*

The Over-the-Counter Hearing Aid Act of 2017 would make certain types of hearing aids available OTC and remove unnecessary and burdensome requirements that currently create barriers for consumers who could benefit from hearing aids.

HLAA is issuing a **Call to Action** to ask for your help in sending Congress a message that passage of this bill would be life-changing for the millions of Americans who don't seek help for their hearing loss simply because they can't afford to. You – we – now have the opportunity to influence Congress to change that. We have created a [new section of the HLAA website](#) entirely devoted to OTC hearing aids. It includes information on what exactly an OTC device is, what all this means to people with hearing loss, and more, and what you can do to help, as well as useful links.

Comments from Rochester Chapter members.

**Dan Brooks:** I feel it is a step in the right direction for those with moderate hearing loss. It will help drive some of the cost down and will hopefully reach more that are in need. It might generate more awareness as well which is always a good thing.

**Al Suffredini:** There are a number of things I'm worried about with this law. Number one is who determines who has moderate hearing loss. Also will these devices do more damage to people with hearing loss than help.

It would be far more important, as far as gaining benefits from an aid that is properly diagnosed for an individual, to have politicians have Medicare support in paying for hearing aids. If not all maybe a percentage. When Medicare became law, sometime in the late 60's, the litmus test was this—"will hearing loss cause death!" Obviously not. But that was back when hearing aids cost far less than they do today. But even so, being so far less expensive, and crucial in communication, it should have been allowed. Medicare pays for sexual dysfunctions, but not hearing aids. I could go on.

But truly, my major concern is about people who have lost some hearing and buy these devices, and possibly are doing more damage to their hearing. If the people who purchase these OTC aids find them worthless or difficult in various situations, will they in the future (should they need a different hearing aid) will they fail to go further to an appropriate hearing professional to be fitted, or even come to HLAA as an informative and helpful resource.

## CUTS TO BUDGET FOR HEARING RESEARCH

*By Ginger Graham*

*(suggested by Fred Altrieth and Bob Sickmond)*

Hearing Health Foundation (HHF) is deeply concerned to learn the Trump administration has proposed an 18% cut to the budget for the National Institutes of Health (NIH).

Such a cut would be devastating for all medical research--including hearing research. As an advocate for the millions of Americans who have hearing loss we are especially troubled.

A drastic decrease to the funding of hearing research would disrupt the efforts of the many hearing researchers who dedicate their lives to finding cures and treatments for hearing loss, tinnitus and balance disorders.

We need your support. Financial support is always needed and welcome--but in this case we are asking for you to contact your representatives to let them know that you oppose cuts to the NIH (and in fact support increases to the NIH's budget).

If you are passionate about funding the research that will lead to cures for hearing loss and balance disorders, now is the time to act. Please join us in contacting your Senators and House of Representative's offices today.

Mention of goods or services in articles or advertisements does not mean HLAA endorsement, nor should exclusion suggest disapproval.

## “MY STORY” – A Personal History

By Suzanne Johnston, MA., CCC/SLP  
Speech/Language Pathologist



I've always been proud to be a “life-long learner”--valued intellectual curiosity and challenges, and respected the process of learning new skills and developing new interests. However, I didn't expect my efforts at “life-long learning” to include how to personally deal with a sudden, significant hearing loss. On the other hand, I feel like fate has long been preparing me to deal with this loss.

From the start of my career in speech pathology, I was most interested in working with folks who were deaf/hard-of hearing. I also went to seminary and was ordained a deacon in the Episcopal Church, with my ministry being an advocate for deaf and hard-of-hearing in the Rochester diocese. As a speech pathologist at Strong Memorial Hospital, I worked closely with the Cochlear Implant Team. I volunteered at Rochester School for the Deaf and I remember thinking how, even though I knew a lot about deafness and hearing loss, I didn't *truly* understand daily life of being hard of hearing or deaf, and felt that was a disadvantage, really. I became familiar with HLAA and was pleased to be asked to join the Professional Advisory Committee and then asked to sit on the Board of Directors, but I was one of the few with normal hearing.

A few years ago, I began to notice tinnitus and very slight changes in my balance. Because of all the work I had done with those with hearing loss, I was particularly sensitized. A hearing test and further testing were abnormal. An MRI confirmed an acoustic neuroma/vestibular schwannoma – a benign tumor in the auditory system. Because I had pursued diagnosis early, my tumor was small, fortunately. My treatment caused rapid and debilitating hearing loss and tinnitus in my treated ear, and significant balance issues.

Looking back, I feel that I have somehow been preparing for hearing loss my whole life...but I was right in understanding that you can't TRULY know

what those with hearing loss experience on a 24/7 basis until you actually have to deal with it yourself. Now, I miss auditory information in noisy places. Now, I am reluctant to ask someone to repeat themselves for a third time. Now, I wonder how many people think I am ‘antisocial’ when I am just not hearing them. But now, my advocacy comes from a different and personal place, with a new authenticity and energy. I feel fortunate for that. And, I am grateful to already be part of an organization and a culture which surrounds me with people who are supportive and understanding.

Through HLAA and the Rochester/Monroe County Council for People with Disabilities, I am proud to represent those with hearing loss in our community. My husband, who manages the construction for the Rochester airport, now has learned (more than he wants to know!) about the needs of people with hearing loss and how to integrate communication accessibility into his work. My three children now realize that they need to take on greater responsibility for getting their message across – not speaking to me from another room, looking at me when they talk, etc. It's a lot of work, in fact it's exhausting most days.

I never imagined that my ‘life-long learning’ would take the form of *these* challenges to my life, but I am running with it!

## NEW SLATE OF OFFICERS 2017-2018

By Cindy Kellner, Chair, Nominating Committee

The committee is pleased to announce the new slate of officers for our chapter, from July 1, 2017 – June 30, 2018.

President:	Sue Miller
Vice-President:	Art Maurer
Recording Secretary:	Elise de Papp, M.D.
Corresponding Secretary:	Carol Loftus
Treasurer:	Gerry Loftus
Asst. Treasurer:	Jo Owens

With many thanks to these folks for stepping up to lead our chapter in future months!

## HEALTH FAIRS – NEED YOUR HELP!

*By Trish Prosser*

Do you have a couple of hours to spare perhaps 4-5 times a year? Do you like to meet and have conversations with others? If so, you could have the opportunity to educate the public about HLAA. Our Chapter can greatly benefit from your assistance with our local Health Fairs. Participation in these Fairs allows us to share our mission with others in our community. So often people hesitate to talk about hearing loss; however, given this venue, it becomes easier to discuss this topic.

In providing a display of educational handouts you would be reaching out to those who have questions regarding their own hearing loss or that of a loved one. You might be the person who is instrumental in making all the difference in someone else's life.

Please consider this rewarding opportunity to spread the good news about our Association. No experience needed, and you'll be working with members who have done this before!

Sign-up sheets will be available at our monthly Chapter meetings. Also, you may contact Trish Prosser for more information and to sign up: [Ppross240@aol.com](mailto:Ppross240@aol.com) 585-305-1763

## BUFFALO WALK4HEARING

*By Carol Loftus*



Hope everyone read my Walk4Hearing article in our April Newsletter. Yes, the Walk has moved to Buffalo. Now I would like to give you the particulars about the

**Walk** and a fun-filled **Kick Off**, also to be held in Buffalo.

The Buffalo Walk4Hearing will be held Sunday, October 8, at Delaware Park. Registration opens at 10:00 a.m. with the Walk starting 11:00 a.m.

A Kick Off will be held August 13 at the Big Ditch Brewery (Buffalo) from 1:00 p.m. to 3:00 p.m. Planning for both events is actively ongoing.

Although the Walk has moved to Buffalo, ALL ARE WELCOME to join those from Buffalo at the Kick Off and the day of the Walk.

Let's come together to support the Walk and the Rochester Chapter; 40% of your Walk donations can be 'designated' to the Rochester Chapter by team captains, walkers, and those who choose to donate but not walk.

Please visit the HLAA National website for ongoing postings -- [www.hearingloss.org](http://www.hearingloss.org)

Should you have any questions about the Kick Off or the Walk, please feel free to contact me at [cloftus3@gmail.com](mailto:cloftus3@gmail.com). Details and directions will be in our September Newsletter.

## HEARING AID TAX CREDIT

*By Ginger Graham (suggested by Elise de Papp, M.D.)*

HLAA Prioritizes Legislative and Advocacy Agenda for 2017; Takes Focus Off Hearing Aid Tax Credit Legislation – February 7, 2017

Since 2003, HLAA has supported legislation that would allow consumers to receive a tax credit for the purchase of hearing aids. The Hearing Aid Assistance Tax Credit Act (Senate bill S.48), reintroduced in the Senate on January 5 by Sen. Dean Heller (R-Nev.), would provide a non-refundable \$500 tax credit for the purchase of a single hearing aid, or \$1,000 for two, once every five years. In the past, a version of the bill introduced in the U.S. House of Representatives included a \$200,000 per year income eligibility cap. A bill has not yet been introduced in the House.

Several iterations of the tax credit bill have been introduced over the span of nearly 14 years, and none have passed. HLAA has therefore decided to focus its efforts and resources on initiatives that we believe will have a more far-reaching impact. Go to: [www.hearingloss.org/advocacy](http://www.hearingloss.org/advocacy)

JUNE will be our last Newsletter until September.  
Due date for articles for the June edition is April 30<sup>th</sup>.  
Ginger, Michelle, and Janet get a well-deserved break in the summer!

**ANNUAL DINNER**

*By Sue Miller*



We'll all have the chance to come together on **Tuesday, May 23<sup>rd</sup>** for the Annual Dinner of the Rochester Chapter of HLAA. From **6:00 to 9pm**, we'll get to know our

scholarship winners and their families. And, recognize just some of the people who make a difference to our Chapter in the Rochester area by presenting 3 awards.

The Cobblestone Creek Country Club has done a superb job in past years with service, hearing accessibility and scrumptious food.

You will enjoy being part of this fabulous evening!

Please sign up by **Thursday, May 18<sup>th</sup>** using the form included [here](#). We hope to see you there!

**Please join us!**

**Tuesday, May 23, 2017**

**Cobblestone Creek Country Club  
100 Cobble Creek Road, Victor, NY 14564**

**6:00 to 9 P.M.**

**Spouses/guests welcome!**

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- (1) 6 oz. Bavette Steak with Maiter d'butrer, green beans and whipped potatoes**
- (2) Classic Chicken French, whipped potatoes and green beans**
- (3) Vegetarian – Vegetable Napoleon (grilled vegetable stack)**

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**\$26.00 per person (includes gratuity)**

Questions? Please email, or call, Sue Miller at [SusanLeeMiller39@cs.com](mailto:SusanLeeMiller39@cs.com); or, phone, 585-924-8933.

**HLAA ANNUAL DINNER  
Reservation Form**

**Name:** \_\_\_\_\_

**Address** \_\_\_\_\_

**Phone or E-mail** \_\_\_\_\_

**Dinner choice** \_\_\_\_\_

~~~~~

**Guest:** \_\_\_\_\_

**Dinner choice** \_\_\_\_\_

~~~~~

**2nd Guest:** \_\_\_\_\_

**Dinner choice** \_\_\_\_\_

**Dinner reservations will be accepted until  
Thursday, May 18<sup>th</sup>**

\_\_\_\_\_ Dinners @ \$26 each = \$ \_\_\_\_\_

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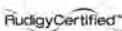
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**HLAA Membership Information**

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 hard of hearing, we welcome everyone to our chapter meetings whatever their hearing ability. For more information, Call **585 266 7890**

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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*

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### **If You're New, This is for You.**

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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 Loss Magazine, holds annual conventions, a Walk4Hearing, and more. Check out: [www.hearingloss.org/](http://www.hearingloss.org/).

The Rochester Chapter 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 House 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](mailto: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!*