



The newsletter of the Hearing Loss Association of America, Albuquerque Chapter

# WIRED FOR SOUND

## Clinical Trials of Potential New Therapies for Hearing Loss Are Out There. Here's How To Find Them

*Julie Upboff, Senior Manager of Clinical Operations, [Frequency Therapeutics](#)*

*From HLAA home page*

Clinical trials play a critical role in bringing new medicines to people who may benefit from them. With hearing loss, clinical trials of therapeutics are a very recent development. Only in the last few years have we been testing potential *medicines* (not devices) to restore hearing to those with certain types of hearing loss.

When I share what I do—manage [clinical trials](#) of a potential hearing restoration drug—even family and friends are surprised to hear that such technologies are no longer science fiction. In fact, a handful of companies are testing potential drugs for hearing loss currently, with others preparing to begin clinical trials in the next few years.

Here are a few ways to stay informed on new clinical trial opportunities:

1. Visit [ClinicalTrials.gov](#), an online resource maintained by the National Institutes of Health

For those living in the U.S., the [ClinicalTrials.gov](#) website is a searchable database of clinical research happening across the country. You may search by health condition, sponsoring company, and/or any other terms to find relevant clinical studies that may be of interest to you (As an example, you can find trials of Frequency's drug candidate, FX-322, by



searching for it by name).

2. Talk to your ear, nose and throat doctor or audiologist.

Your hearing healthcare provider is also a great resource for you in your treatment journey. Just as you speak with them about the latest advancements in devices and other technologies, don't hesitate to ask your provider about new research and opportunities for clinical trial participation as a possible option. This includes veterans who receive their care at the VA.

3. Grow your network by joining advocacy organizations like HLAA.

Consumer advocacy organizations like the Hearing Loss Association of America play an important role in amplifying the latest updates for their communities. If you're not already a member of an [HLAA Chapter](#), consider joining one. The strength of this special community lies not just with the national team, but with the presence of chapters spread across the nation. This network can help you to stay informed of innovations that could improve both hearing clarity and quality of life.

If it is of interest to you, I hope you will explore one of the many avenues to finding clinical trials for hearing loss. Of course, every trial has its own criteria for participation, and if you are not a fit for one, it is very possible you could be a fit for another.

By participating and encouraging oth-



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people with hearing loss

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**Home page:** [hearinglossabq.org](http://hearinglossabq.org)

[Hearing Loss Association of America](http://hearinglossabq.org)  
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**17 Feb Meeting** 10:00 AM To Noon—**Cancelled****February Meeting Cancelled** 😞

*Mary Clark*

After having been out of the role of planning programs for a few years, I'm re-discovering that planning programs can work both ways. Our February program fell through, and without a solid backup plan, we have decided to cancel our February 17 zoom meeting. With the help of our dedicated board, I do have some great topics to work on, so stay tuned for announcements for the rest of the year!

The topics we're working on include

- Learning about the new apartment building designed for deaf and hard of hearing tenants here in Albuquerque
- Cognition and hearing loss, and why the newest "standards of care" for hearing testing suggest a cognition test
- Lipreading is always a popular topic so we're searching for just the right program for you.
- Update on a federal law that requires those admitted to skilled nursing or rehab facilities are tested for hearing loss and why this is seldom done
- Captioned phones, including cell phone call captioning apps
- A report about how the brain is rewired after hearing loss—a new field of research study
- A users' perspective on cochlear implants
- Hearing loss in everyday life
- Hearing loss in healthcare

We have some speakers identified for some of these topics, but the work is in engaging them and scheduling them.

Next November, we will have Gael Hannen share a program on setting goals for our hearing loss.

Obviously, if you have a topic or a speaker you'd like to share please let me know at [mary@mandgclark.com](mailto:mary@mandgclark.com)

The HLAA ABQ Chapter could use some help to resume hybrid meetings (for example, with hospitality), as well as some new blood. You already know our dedication to providing the best information, advocacy, education and support for people with hearing loss. You can ease your way into volunteering and learn how this works. Just email one of the board members (listed on the left). You may also use the chapter email: [HLAAbq@gmail.com](mailto:HLAAbq@gmail.com).

ers to participate in clinical research, you are helping to advance science. Currently, there are no approved medicines for the most common form of

hearing loss – sensorineural hearing loss. But there may be some day, and clinical trials are the path that will take us there safely.

## Loop People, Loop Places

*Ginevra Ralph*

### **Five steps to loop a noisy store**

Some time ago I told you about a friend who “looped her life” with her portable hearing loop—at yoga, in the car with the grandkids, in business meetings, etc.—and THEN she looped her grocery store checkout lanes! Her parent company, Grocery Outlet, has now published her story in their corporate newsletter to all of their franchises, along with [5 Steps to Loop a Supermarket](#). It can work for any store: 1) designate a lead staff person; 2) ask staff and customers where they can’t hear; 3) install a counter loop in key locations; 4) teach staff and test it with your customer advisors; and 5) promote it like crazy!!! Then everyone pay at least one visit and compliment the store on their accessibility.



## NEWS RELEASE

### **Many with hearing loss don't use assistive communication technology — why not?**

Since the passage of the Americans with Disabilities Act (ADA), assistive listening systems (ALS) have been mandated in many public gathering places. Various forms of captions, though not mandated, are requested and sometimes provided. Millions use these technologies. Millions more could, but do not.

The Committee for Communication Access in America (CCAA) has conducted a survey to investigate the matter, and today released a report of their findings. That detailed report plus graphs and a wealth of other information gathered during the survey is also posted at the group's website ([www.ccaa.name](http://www.ccaa.name)) for public review.

**Smith's Community Rewards Shop** at Smith's with their Rewards card, and Smith's will make a donation to HLAA Albuquerque chapter. You get your usual rewards points.

1-800-444-8081, opt. 3 to sign up or re-enroll.

The HLAAAbq NPO number for Smith's is **NC419**.

The survey was a retrospective cross-sectional study of individuals with hearing loss or some other hearing-related condition. The 1,519 respondents were heavily weighted toward people with a severe to profound hearing loss, so many questions were cross-tabbed to get an accurate picture of various subgroups. The intent was to acquire accurate information on the preferences and use habits of hard-of-hearing people when utilizing assistive communication systems. That information will enable providers of services to people with hearing loss to inform clients of the many benefits of the various assistive technologies. In addition to information and observations on assistive listening

Yearly dues are \$15 per household.  
They are due in January.

and captioning systems, the survey collected detailed information on:

- > Degree of hearing loss
- > Age and years using hearing devices
- > Type of hearing devices used
- > Features of those devices
- > Affiliation with hearing loss support groups
- > Assistive devices selected to supplement hearing aids.

Among the many surprises in the findings was the preponderance of people with severe to profound hearing loss as participants, and the importance of communication technologies to them in comparison to people with milder hearing loss.

Another was a preference for captions over an ALS by this very hearing-disabled group. The survey reinforced the fact that hearing loops are the preferred ALS for the hard-of-hearing. Not surprising was that over half of respondents learned about telecoils elsewhere than from their hearing care provider.

**QUESTIONS:** *Stephen Frazier, 505-401-4195*

**About the Committee for Communication Access in America:** *The CCAA is an ad hoc committee of seven nationally known advocates for people with hearing loss who came together to gather and then share information on the use of assistive communication technology.*

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## Santa Fe Chapter

### Topic: CapTel Captioned Telephones and Apps

Thomas Sena, Relay New Mexico Outreach Coordinator, will present about CapTel phones and new developments in terms of CapTel for iPhone and Android.

**Santa Fe Association of Realtors,  
510 N. Guadalupe St.**



**(just up from Jinja Bistro  
north of DeVargas Mall)**

**We have ASL  
interpreters as well as a  
hearing loop.**

**All meetings are free and no  
reservations are needed.**

More information: John Hooper,  
johnhooper.ref@gmail.com, 505-603-2994

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*Since the Albuquerque February meeting got cancelled, here is an option from National HLAA:*

### How can over-the-counter hearing aids help?

**OTC 101: Ask the Experts on February 20,** at 2:00 ET (12:00 MT)

This exciting new class of products may provide another pathway to treatment for some adults with mild-to-moderate hearing loss. We're presenting a series of four webinars through spring 2024, designed to answer your questions and clear up confusion.

The February webinar features Charlotte S. Yeh, M.D., chief medical officer for AARP Services, Inc. and Kelly King, Au.D., Ph.D., audiologist and program officer at the National Institute on Deafness and Other Communication Disorders (NID-CD) of the National Institutes of Health (NIH), on a panel moderated by HLAA Executive Director Barbara Kelley.

This complimentary event will be captioned, recorded and open to all.

You may register [HERE](#)





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**Support the Hearing Loss Association of America (HLAA). Become a member TODAY!**

The Hearing Loss Association of America is a volunteer association of Hard of Hearing people, their relatives and friends. It is a non-profit, non-sectarian educational organization devoted to the welfare and interest of those who cannot hear well. Membership in the national organization is by annual dues, which are separate from the annual Chapter fee paid to your local chapter. National membership includes a subscription to the bimonthly publication Hearing Life.



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**Dues:** \$15 per household per calendar year (Includes newsletter subscription)

**Online:** <https://www.hearinglossabq.org/electronic-pay>

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