

Say What Club NEWSLETTER

July 2026



Our Mission

The Say What Club is dedicated to enhancing interpersonal communication for people who are hard of hearing, deafened, or have a serious interest in hearing loss, with goals of:

- Providing for mutual sharing of coping and "life" skills;
- Reducing feelings of isolation, frustration and despair;
- Enhancing feelings of self-concept and optimism;
- Educating SWC participants and the public about all aspects of hearing loss.

Convention 2026 - Summer of Love San Francisco - August 3 - 6

San Francisco here we come...

For many, this is the first time they are visiting the city by the Bay, the San Francisco Bay, that is. The Commons email group is busy with introductions, comments and suggestions of where to eat and where to go for fun in the city and the surrounding areas. The conference is being held at the Grand Hyatt at Union Square.

There are lots of planned activities, not to mention all the unplanned ones that are bound to happen. There will be vendors displaying their tools and sharing their tips. Lots of speakers sharing their experiences and knowledge.



Additionally, there will be a few excursions - a Blue and Gold Fleet Sunset Cruise along with a trip to the theater to see a captioned performance of Hairspray. Get your tickets to both of these now to join in the fun.

As always, the conference is a time where all of us can be together in a group of people who understand what it means to be hard of hearing. We get together annually to meet new and old friends.

For more information about the convention, check out our Convention Web Page: [2026 Convention](#). This has information about the show, cruise and more.

Many Thanks to **Trader Joe's** for donating bags for our conference.

BIG CHANGES....we've moved the lists. We are now on Google lists - this is all due to the fantastic work that Marty and Ilene did in identifying all lists and their members and moving them into the new structure. This was an amazing amount of work done in only a few days and was incredibly smooth. This change will improve our communications in many ways ... no more bouncing and missing emails, removal of restrictions on picture sizes, and making it easier to include attachments. Not to mention decreasing our expenses and RENEWALS are now a thing of the past.

BIG THANKS TO MARTY AND ILENE!!!

Safety First - Driving Tips

You can safely drive with hearing loss. Driving is mostly a visual task. Many states let you drive without restrictions. You just need to take extra steps to stay aware of what is happening around you.

One of the best things I've done is to pick up a card indicating I am hard of hearing. If pulled over, I display this so the emergency team can see it. It is important for emergency personnel to know you are hard of hearing to avoid any communication issues. I also have a tag on my keychain, just in case.

Key Safety Rules

- **Wear your devices:** Always wear your hearing aids or cochlear implants while driving. Check your battery and volume levels before you start. Carry spare batteries or devices in the event of battery drain. Pull off the road to switch out batteries.
- **Stop the noise:** Turn down or turn off your car radio. Roll up your windows to block out road and wind noises.
- **Use extra mirrors:** Add wide-angle or blind-spot mirrors to your car. This helps you see cars you might not hear. Mind you, Electric Vehicles are hard to hear for everyone.
- **Be Aware - Scan the road:** Check your mirrors frequently. Watch for flashing emergency lights and changes in traffic.
- **Look at your dashboard:** Pay attention to warning lights and your turn signals. Check turn signals after use to make sure they are off.
- **Avoid distractions:** Do not use your phone while driving. Ask passengers to keep talking and moving to a minimum. Pull off the road to take or make a call if necessary. **NO TEXTING!**
- **Take breaks:** Driving can cause mental fatigue. Take frequent breaks on long trips.

Visit an American Hearing + Audiology clinic or read their tips on Driving with Hearing Loss to prepare for the road.

Learn more about safely operating a vehicle by exploring resources on [The National Council on Aging](#) (NCOA).

Discover extra tips for the road from the [Heuser Hearing Institute](#)

If you are pulled over, make sure they know you are hard of hearing and need accommodations - do not agree to anything without seeing it in writing. Use whatever transcribing tools you have available. **Stand up for your rights!**

This month's committee Web

Have you ever wondered what the Web Committee does? The SayWhatClub website at www.saywhatclub.org is maintained by volunteer Web Committee members-- Audrey Dessauer, Vicky Harland, Michele Linder, Lorne Smith, and Kim Ward. Ilene Morales is our board liaison.

Our website is often the first place people find the SayWhatClub when searching online for hearing loss resources. It also supports membership registration, convention registration, donations, sponsorship logos, and provides information about our organization.

The site includes six main sections: About, Conventions, Blog, Join, Resources, and Donate. Visitors to our web pages can learn about our history and mission, register for conventions, read our blog, join the club, access hearing-loss resources ranging from hearing aids to service dogs, and much more!

Throughout the year, the Web Committee updates our web pages to keep information current. The site is built on WordPress, allowing volunteers to make changes without coding knowledge.

A significant portion of our work involves convention planning. While members are currently registering for the 2026 convention in San Francisco, the Web Committee is already preparing a "Save the Date" page for next year's event. Throughout the year, we update convention information, including hotel and registration details, speakers, workshops, sponsor logos, and activity sign-ups. Although our goal is to launch the new convention registration page each January, work on it begins several months in advance.

Occasionally, technical issues arise. Fortunately, the SayWhatClub works with a web designer, Warren Laine-Naida, who monitors the site's health and assists with more complex updates and troubleshooting. Warren helped us develop our current web page in 2023. We are grateful for his expertise and support when we need it.

Editing the pages on our website is a never-ending process, but it is fun. We are always looking for volunteers. If you're interested in helping us out, let us know!

Editor's Letters by Deanne

While I was thinking about what New and Exciting things we could add to the NEWSletter, I decided we needed a place for communications...from both the NEWSletter Team and **ALL OF YOU**. This NEWSletter is for all of us, to talk about new things, share technology, tell stories, introduce and re-introduce members that have been a significant part of the club and more. While I've been a member for only a few years, I've learned and shared quite a bit by being part of this group. It all starts with communication. We have a number of ways the groups chat...whether it be facebook or thru the distribution lists. Facebook provides the ability to lurk and listen, but the lists give you the opportunity to make friends, help others and in some cases just say what you are thinking. Being a part of this group .. and the lists .. has been a wonderful thing for me; they helped me make the decision to move forward with my cochlear implants and when I needed help with my doorbell, people were there to share what they were using. We are all in this hearing loss journey together, it may be a slightly different path, but we are all faced with similar obstacles and have overcome them. Participating in the email chats is essential to this group and it is what makes this group unique. There are other hearing loss groups, but they don't have the email lists that we do.

I just wanted to share a bit of what this group means to me and introduce this new area where we can share our thoughts and our journey. By the way, we have started a NEWSletter email group so you can share these communications with us - send newsletter articles to newsletter@saywhatclub.org So, please send us what you would like to see in the newsletter....

I'm looking forward to hearing from you!....Deanne

Each newsletter will highlight one SWC subscriber
This month...

Chelle Wyatt



New book on hearing loss: *61 Days of Hearing Loss: Life Lessons to Manage Communication* by Chelle Wyatt

Thank you to SWC with all my heart. In the late 90s, I knew there had to be more than just hearing aids for hearing loss. Hearing aids alone left a lot of gaps in communication which left me feeling defective. In those early email lists, I found a path forward with hearing loss. Thanks to those few years with SWC, I dropped off the lists to pursue other adventures in life.

In 2007, my hearing dropped into the severe range. My coworkers and family supported me with the new level of hearing loss which

helped me so much! When I moved in late 2008 to another city, everything changed and nothing seemed to work well. That's when I looked up SWC again in 2009. The organization was still active and that was a relief. SWC gave me immediate, daily relief via emails. Because I lived in a big city now, I also had local support through monthly meetings and provided classes around hearing loss. Slowly I crawled out of the hearing loss hole and became active in life again...which is why I wrote the book.

"[61 Days of Hearing Loss: Life Lessons to Manage Communication](#)" came into being because I wondered how many times a day I managed communication. Managing communication is every day and multiple times a day. What if I tracked it? For the last two months of 2024, I kept track and found most days are the same thing over again. Getting people to face me when talking is the biggest hurdle. That's repetitive so I narrowed down each entry to one item a day. With all my know-how of hearing loss, you might think my home life was smooth. Not so. Sometimes family is the hardest to get onboard and that's normal. Once "61 Days of Hearing Loss" was edited, I let my husband read it warning him he was not on his best behavior. After reading it, he didn't ask me to change a thing, because it's how it went down. They were teaching moments after the fact. He started to clear up some of the communication obstacles. He tells people, "I'm the main character." There's something about seeing it written down.

It's not just him, or other people. There were times I forgot everything I knew, getting caught up in a bad cycle. Afterwards, I wondered, "why didn't I stop that?" Well, we aren't at our best when tired and hangry. We're human. It's progress, not perfection. Stop that self criticism. We are too hard on ourselves. I remind myself that I'm better than ever with hearing even worse. My new book shares real life experiences and not all of them are happy and joyful.

Another focus in the book is creating awareness of strategies and technology. So few people know the limits of their hearing devices (hearing aids or cochlear implants) so those are highlighted in the book. Once we know the limits, we can use strategies and workarounds to get the communication we need. There is so much available via technology. For example, few people know how much accessibility sits in their hand via smartphones. Other days in the book feature me educating hearing people on what works and what doesn't. Then there's emotions that go with hearing loss and that's noted as well.

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Tracking my communication needs in categories showed me that I use strategies more than technology. Hearing aids are a part of my everyday life (almost everyday which is also explained in the book). Strategies are what make my life more successful WITH hearing aids. Tracking communication helped me see the repetitive cycles and it helped my husband. Would it help others to do it too?

Hearing Loss LIVE! created a [Seven Day Worksheet](#) to give others a chance to track communication breakdowns. Write your daily issues down and give it some emotional rant space. The worksheet reminds us to come back to it, when calmer, to evaluate the situation. How can we make it flow smoother next time? Then at the end of the week, we challenge people to share it with their hearing partner(s) for awareness of daily exchanges.

If you have the book, we encourage you to share that with hearing family and friends. Like Chelle's husband, it might give them more insight into the process. In fact, here's a review left on Amazon by a hearing family member: *"This book is a great insight into the world that the Hard of Hearing community exists in day-to-day. Although I am not Hard of Hearing, learning about this as the author journeys through 61 days of her world was very enlightening. It was also a fun read because the author has a great sense of humor that is shared through her stories. My guess is that most of us have someone that is Hard of Hearing in our lives. Reading this book provides gems of information that can be applied when encountering these experiences."*

Sneak peak: Here are four entries from the book which are divided into four parts: Technology, Strategies, Awareness and Emotion.

Part 1 Link: <https://hearinglosslive.com/61-days-hearing-loss-part-1/>

- Day 11 Strategy - A communication breakdown turns into a learning experience. How to evaluate what went wrong.
- Day 24 Awareness - Hearing breaks are needed! Don't let your family assume you're checking out from them. Help them understand it from a hearing loss perspective.

Part 2 Link: <https://hearinglosslive.com/61-days-of-hearing-loss-part-2/>

- Day 29 Emotion - Communication in the car is challenging, especially when the other person doesn't do their part.
- Day 41 Technology - Warning chimes in hearing devices can be adjusted, i.e. low battery and missing hearing aid.

Chelle will be at the San Francisco SayWhatClub August 3rd through 6th. She'll bring some printed copies with her to preview, or buy. SayWhatClub conventions are a great way to connect with the Hard of Hearing community. This is where we can learn more about new technologies through sponsors. Workshop presenters share knowledge and strategies. If you haven't been to one yet, put it on your bucket list.

Need any help with the SayWhatClub emails? Do you want to switch your List or change from emails to a daily distribution list? Or do you just need a helping hand. Here are the List Reps by group:

- | | |
|-----------|--|
| • Connect | Leslie Cotter, EMPTY** |
| • CI | Judy Heimbach, Linda Binns |
| • Explore | Martha Wilson |
| • Forum | Carol Hansing, Bet Lareau Whitcomb |
| • Vistas | Ruthann Saunders, Linda Binns |
| • World | Lorne Smith, Nancy Fenstermaker, Pat Dobbs |

****Are you interested in helping out...we need a second List Rep for Connect. Tasks include: Contacting newcomers and making sure that the conversation on the list flows are the two major components of the job. Resolving any disputes that may arise. Contact Linda Binns for more information**

Today's Hearing Loss articles will focus on Reverse Slope Hearing Loss by Neil Baumann and a write up about the Speech Banana on page 8.

My Extreme Reverse Slope Hearing Loss

by Neil Bauman, Ph.D.

Imagine having a hearing loss so weird that you can't hear/understand a person talking just four feet in front of your face, yet at the same time you can hear a whisper from across a large room. That's the rare kind of hearing loss I was born with. It is technically known as a low-frequency hearing loss but is commonly referred to as a reverse-slope hearing loss (the opposite of the common ski-slope loss).

Reverse-slope hearing losses are rare. My loss was not only a reverse-slope loss but was an extremely rare version of a reverse-slope loss since I had an incredible range in my hearing of 110 dB from the softest low-frequency sound I could hear to the softest high-frequency sound I could hear. (The more common form of a reverse-slope loss only has a range of around 30 dB.)

Extreme reverse-slope hearing losses are almost always due to genetic mutations. They are non-syndromic (no obvious genetic variations associated with it), autosomal, dominant hearing losses. This means only one parent has to carry the gene in order for their offspring to have this kind of hearing loss. Since only one parent has to carry this gene, each child born to that family has a 1 in 2 chance of inheriting this hearing loss. In my case, I inherited my hearing loss from my mother.

Incidentally, the gene responsible for this kind of loss seems to mutate out of nowhere, continues on for 4 to 6 generations and then disappears again. I've seen this pattern in several other families with extreme reverse-slope losses.

In my family those known to have this reverse-slope hearing loss are my maternal grandfather, my mom, myself and my brother, my younger daughter and my brother's older son and his boy. I'm the only one to have this incredible range in hearing, but my daughter is a close second.

Fortunately, this hearing loss won't go further on my side of the family since my grandsons from both of my daughters have normal hearing. Remember this hearing loss is caused by a dominant gene, and since my grandsons have normal hearing, they obviously don't carry this defective dominant gene. Thus, going forward their children will also have normal hearing (all things being equal).

When I was younger, I had about an 80 dB (severe) hearing loss in the low frequencies, but my hearing loss morphed into a hearing gain since I could still hear at an incredible minus 30 dB in the high frequencies—30 dB above the 0 dB line on an audiogram. That meant I could hear a high-frequency sound so faint that the sound pressure in the air had to be amplified 1,000 times before

a person with "perfect" hearing could just begin to hear it—yet I was the "deaf" guy with a severe hearing loss in the speech frequencies!

Now that I am well up in age, presbycusis (hearing loss due to aging) has kicked in and my formerly incredible high-frequency hearing is no more. As a result, the high-frequency hearing I relied on most of my life is gone and I am now functionally deaf.

One of the characteristics of having a significant reverse-slope hearing loss is that all of us have normal speech. This fools people into thinking that since we speak flawlessly, we must have normal hearing. The only way you could ever tell is I tend to speak louder so I can hear myself talking, and I may mispronounce a word I've never heard spoken such as putting the emphasis on the wrong syllable.

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Another weird characteristic of having an extreme reverse-slope hearing loss is that volume and tone (frequency) are tied together. Thus, higher notes are always louder. When I was younger, I could not tell the difference between the tone control and the volume control on our stereo. Turning up the tone control gave exactly the same loudness effect to my ears as did turning up the volume control.

Thus, setting the volume of a piece of music to a comfortable level when the music has a broad range of tones was (and still is) impossible. The volume I hear varies from nothing to too loud to stand depending on the frequency of the notes being played—and this is true even when I am wearing my fancy hearing aids. For example, as I am writing this article I am listening to a piece by Mozart. Sometimes I can't hear a sound, sometimes it is a comfortable listening level and sometimes it is much too loud. Thus, to really enjoy music I need the music to basically stay in one octave (high C is my favorite octave) and have more or less constant volume.

Unfortunately, almost no audiologists know how to effectively program hearing aids for my kind of loss. They think they do, but don't—at least I've never met one. Some years ago I was speaking at an audiology convention on this topic, and I asked for a show of hands how many of them had ever had a client with an extreme reverse-slope loss at any time in their whole careers and only one or two hands went up.

The problem is that when you have my kind of hearing loss, my hearing aids have to be set, not the intuitive way hearing aids are normally programmed, but almost opposite to what you would think would be correct. Therefore, if you are interested and want to learn more about reverse-slope hearing losses and the principles on how to properly program hearing aids for this kind of loss, read my comprehensive article on these subjects at <https://hearinglosshelp.com/blog/the-bizarre-world-of-extreme-reverse-slope-hearing-loss/>.

The Benefits of Being a Volunteer

Volunteering is one of the most powerful ways to invest in yourself while making a meaningful difference in the world. Whether you dedicate a few hours a month or commit to a long-term role, the rewards extend far beyond the immediate act of service. We are in need of a few people to help out in various roles within SWC, if you have a few minutes to spare, we'd love to have you as part of the volunteer team.

How Attitude Shifts can Transform your Hearing Loss Journey

I recently read an article from Shari Eberts, author of "Hear and Beyond: Live Skillfully with Hearing Loss" and was inspired to send her a note so I could share a link to her website: [Living with Hearing Loss](#) and mention a few things that we should all remember during our journey..

Shari talks about how difficult it is to have hearing loss and what we must all do to overcome the all of the changes that happen within us - the emotions, isolation, grief, frustration, embarrassment and in some cases, shame. She talks about Mindshifts and what we need to do to overcome these feelings. It's a great read, I've tried to overcome a lot of these issues and help others around me...that's part of why I'm involved with the group and NEWSletter - if you have a minute, I strongly suggest taking a look.

What does a banana have to do with your hearing?

Imagine an **audiogram** — a graph that shows what sounds someone can hear. Frequency (pitch) runs left to right (low to high), and loudness runs top to bottom (soft at the top, loud at the bottom).



The **speech banana** is the curved, banana-shaped area on that graph where **almost all the important sounds of human speech** fall. It covers roughly:

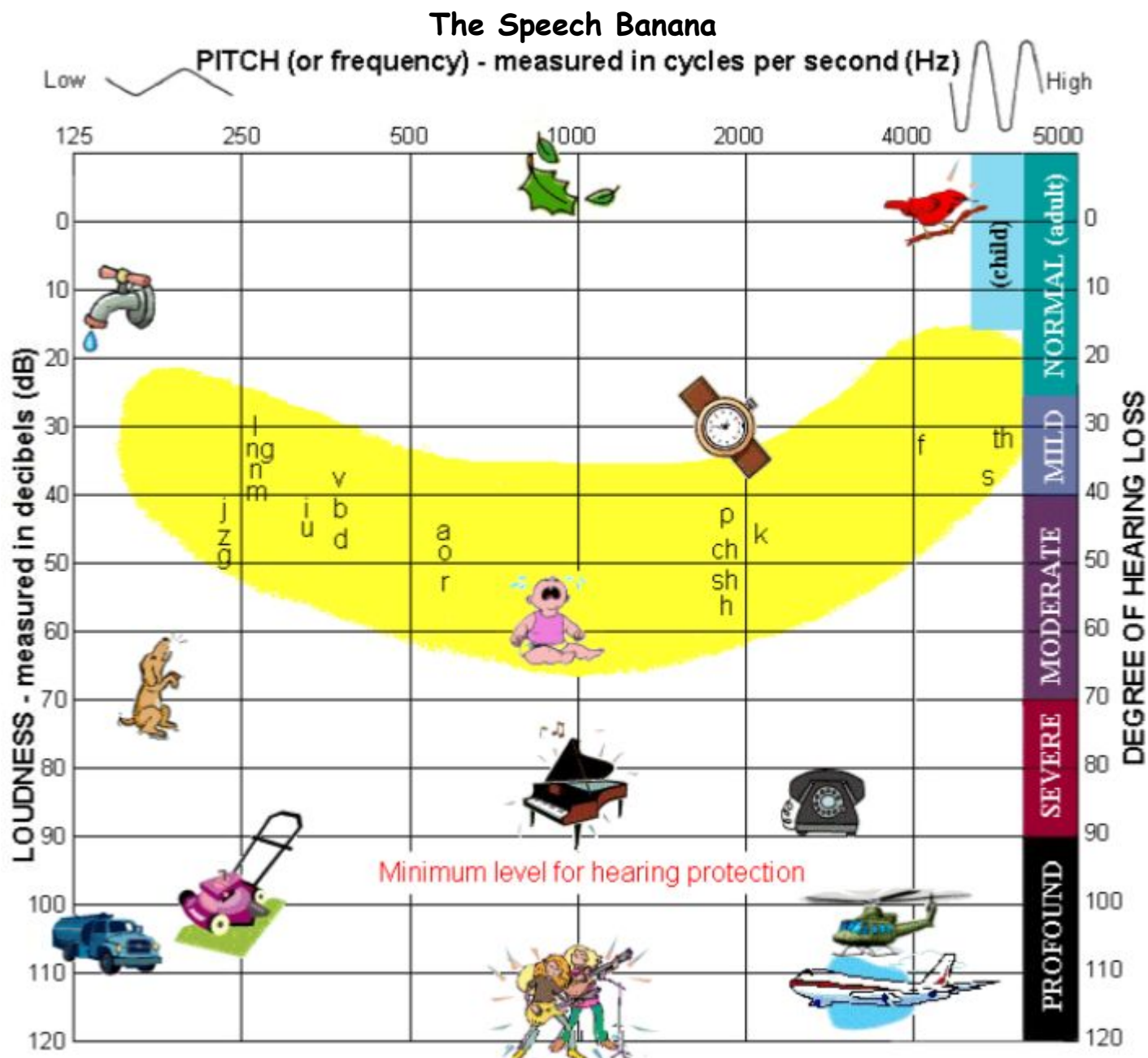
- **Frequencies:** 125 Hz to 8,000 Hz (mostly the mid-range where speech lives)
- **Loudness:** Around 20-60 dB for normal conversation

Vowels (like "ah," "ee," "oo") tend to be louder and lower-pitched (left side of the banana). Consonants (especially soft ones like "s," "th," "f," "sh," "ch") are quieter and higher-pitched (right side, toward the tip).

If hearing thresholds (the points plotted on an audiogram) fall **inside or below** this banana, they miss key parts of speech — even if they can hear other sounds fine. Using your audiogram, overlay it on the Speech Banana below.

Some hearing aids can map sounds from regions you cannot hear to a different area in hopes that will help you hear better. They can do similar mappings with CI's where they will turn off an electrode and others will compensate. Talk to your Audiologist to see if there are options available to you.

Stay tuned for the next Newsletter for a discussion on the Degree of Hearing Loss (right side of chart)



Upcoming Newsletters

WE NEED YOU!!

Do you have something to share about the club, what's happening in the hearing world or ... something else? Do you like to write? Share with us and we will add what we can to the NEWSletter. We need your input for future SWC NEWSletters. Send your ideas and write ups to the newsletter team.

We now have an email for you to contact us:
newsletter@saywhatclub.org

President: Bet Whitcomb
Vice President: Dawn Linder
Secretary: Ann Marie Picardo
Treasurer: Ilene Morales
Board Members: Donna McNary
Mary Ann Livesey
Deanne Pedroni

Read more about [Our Team](#)
Web: [SayWhatClub](#)
Facebook: @SayWhatClub or [SWC Friends](#)

SayWhatClub Shirts

The shirts have **ARRIVED**. Many of you have already received your shirts. For those of you who asked to pick up your shirts at the convention, Deanne will be bringing them to San Francisco. She is also bringing a few spares to sell/raffle as well. Many thanks to Bet, Dawn, Donna and the rest of the Board for making this possible. Thanks also to Lorne for creating the order form.

We hope to see you there!!



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Would You Consider a Donation?

Visit the Donation page on the [SayWhatClub Website](#). We are a 501(c)(3) organization and all donations are tax deductible. Please consider using Zelle or paying by check. If using PayPal, please cover the donation fees.



Every Conversation Matters

For more than 10 years, [InnoCaption](#) has helped people who are deaf, hard of hearing, or have speech disabilities make phone calls with greater confidence and independence. We're excited to be back at SayWhatClub this year and share some of the newest ways we're helping our community stay connected.

More Ways to Stay Connected

Text-to-Speech Shortcuts: Many of our users have shared that listening fatigue can make conversations more challenging, even with hearing technology. Text-to-Speech allows you to type what you'd like to say and have it spoken aloud during a call.

Picture-in-Picture (iOS): Picture-in-Picture keeps captions visible in a floating window while using other apps, so you can stay engaged in the conversation without missing a word.

AI-Powered Features: Our newest AI-powered enhancements help make conversations smoother and easier to follow, giving users more confidence on every call.

InnoCaption Video

[Introducing InnoCaption Video:](#) Many people in our community prefer video calls because they provide visual cues, facial expressions, and a more personal way to connect. That's why we're excited to introduce [InnoCaption Video](#)!

InnoCaption Video helps you stay present and engaged while following every word.

- Real-time captions throughout every call
- Available on iPhone and Android
- Invite friends and family to join
- Designed with accessibility in mind

Visit Us at the SayWhatClub Convention

Stop by our booth to learn more about InnoCaption, explore InnoCaption Video, and see how we're continuing to make communication more accessible for everyone.