

Say What Club **NEWSLETTER**



October 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.

2026 SayWhatClub San Francisco Convention Recap



The 2026 SayWhatClub (SWC) Annual Convention was held from August 3 through August 6, 2026, at the Grand Hyatt San Francisco in Union Square. The event brought together members, first-time attendees, presenters, service providers, and sponsors for four days of community building, workshops, and local excursions. Mike Steele led the convention committee assisted by Ruth & Gregg Gorrin who were the nuts and bolts making San Francisco a wonderful place to gather.

The convention was attended by 64 people, including 24 individuals and 20 couples, alongside interpreters, CART providers, and workshop speakers. This year we had 5 first-time attendees participate, benefiting from the dedicated Newcomers Breakfast on Tuesday morning. In addition, we had 10 vendors and exhibitors participate, including Hearing Loss Live, InnoCaption, Caption Companion, Copper Loop Assistive Listening Devices, Cochlear Americas, Canine Companions,

Leion Hearing, Rylo, Global Alliance of Speech-to-text Captioning, Hamilton CapTel, and Disability Rights California. We were also fortunate to receive sponsorship support from Listen Technologies, Diglo, and Safe'N'Clear.

A highlight for many attendees were the planned social events. This year they included the Welcome Party Reception (Aug 3) held in the 36th-floor Bayview Room with a 1960s theme "Summer of Love". On August 4th, 38 attendees joined the Blue & Gold Fleet Sunset Cruise around San Francisco Bay from Pier 39. Lastly, on the evening of August 5th, 22 attendees attended the captioned production of *Hairspray* at the San Francisco Playhouse.

The vendor presentations, workshops, banquet and keynote are the staples that bring members new and old together, learning new information with our common goal of being able to thrive through communication. The vendors provided interactive exhibitor introductions and booth visits highlighting assistive technology, smart glasses, cochlear implants, hearing service dogs, and hearing loop installations. The workshop sessions were led by Neil Bauman (Musical Ear Syndrome and Audion Preidolia), Sherry Chase (patient-centered audiology), Dr. Gabriel Liboiron-Cohen (Performance Longevity for musicians), Brooke Barry (music perception), and Antoine Hunter (interactive dance & ASL). The banquet, which brings all attendees together for the final gathering was held on Thursday, August 6, featuring keynote speaker Rachel Zemach presenting on "In-Betweeners", followed by the annual Spirit Award presentation awarding Rhonda Edwards for her dedication and volunteerism to the club.

Throughout the workshops attendees had opportunities to participate in a gift card & 50/50 raffle. This year \$4,100.00 was raised.

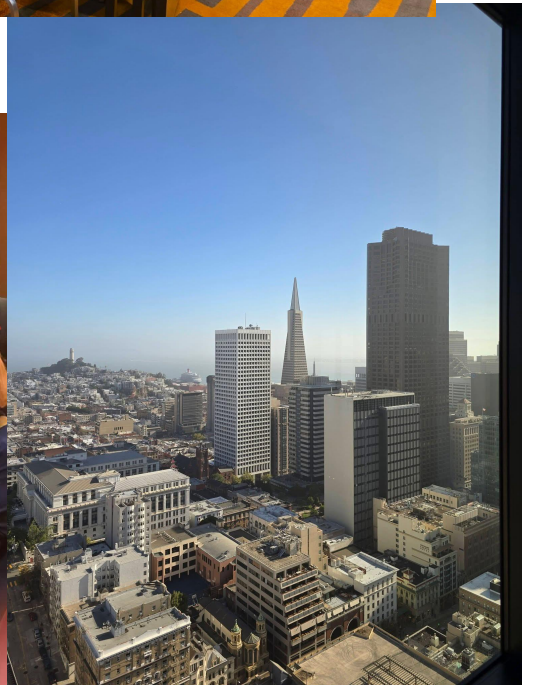
Say What Club attendees leave once again with new and renewed friendships, a bank of hearing resource knowledge to add to existing toolboxes, and fun-filled memories of times spent with cherished friends. Hope to see you in Richmond in May 2027!

Spirit Award 2026 Rhonda Edwards

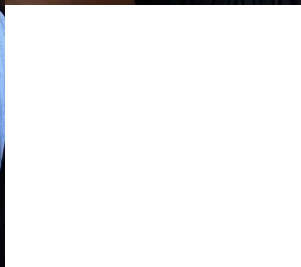


Congratulations to Rhonda Edwards who was awarded the 2026 SayWhatClub Spirit Award. Rhonda was awarded the Spirit Award because she is enthusiastic, cheerful, and demonstrates a genuine warmth and friendship to its members. She has volunteered with the convention committee for a number of years helping with registration, silent auction and activities. Rhonda is a natural 'helper', always willing to help where needed and can often be found behind the scenes helping those in need.

At the Convention



Fun in San Francisco



The **2027 SayWhatClub Convention** will be held from May 24 – 27 at the Hilton Richmond Downtown, 501 E Broad St., Richmond, VA. The hotel room rate, which includes breakfast, is \$188 a night for a standard room. This rate is valid until April 22, 2027. Registration will open in November. Watch for the 2027 convention page coming soon.

***The Butterfly Cage* by Rachel Zemach, A Book Review by Kate Johnston**

I am what Rachel Zemach, author of *The Butterfly Cage*, calls an “inbetweener.”

Inbetweeners or hard of hearing people,

“... have one foot in the hearing world. We have speaking and hearing privileges, but psychologically we are often more confused, and more ambiguous in our actions, trying to lipread; we become used to missing things, to our detriment. By contrast, those in the Deaf community are used to full communication access, through ASL. When in new settings, they request interpreters, and when that’s unavailable they often avoid the situation altogether. Whereas for inbetweeners, a Swiss cheese version of life – full of holes and pretending – becomes the norm.”

I was born with a severe hearing loss but was fitted with hearing aids at the age of three and taught myself to read lips. I went to public schools, where I was always the only one with a hearing loss in my classes, and usually the only one with a hearing loss in the entire school. My friend Judy was born six months after me and was born Deaf from her mother contracting rubella. She lived a few houses away, and we became friends.

Judy’s parents tried for years to get her to talk; I often came by on Saturday mornings and watched Judy sitting with the speech therapist at the kitchen table. The therapist made Judy repeat again and again the words she couldn’t hear. Her parents finally gave up on making Judy into a hearing person and sent her to deaf schools. I often didn’t see her for weeks or months, until she came home for a weekend or for holidays. I don’t remember anyone explaining to me that she was going to school far away, which was why she wasn’t around to play with after school during the week anymore. Her mother learned to sign, but her father only knew a few signs, which could account for Judy not coming home often.

I think my parents looked at Judy and were thankful I wasn’t as deaf as she was. She never learned to read or write well, and her voice was (is) difficult to understand; yet she had (has) ASL, and a ready community.

I think Judy’s parents looked at me and wished she was more like me. I could read and write and was, in general, easier to understand when I spoke. My father didn’t want a child with disabilities and wanted me to be a “normal” child, meaning I could hear normally with my hearing aids (or so he thought) and didn’t sign. I picked up on the idea that using sign language was “bad”. But I struggled to understand speech my entire life (even now with cochlear implants), and I experienced loneliness my whole life. Even now, there’s a small hidden part of me that feels guilty for (a) using ASL; and (b) not being as fluent in ASL as I want to be.

(Judy taught me some signs on her visits home, and I took my first class when I was in my early twenties. During one of those early classes, one of my hearing aids broke, and I was unable to get a loaner. I was also taking a computer programming class at the time, and I thought, “What am I going to do?” I asked the college to provide me with an ASL interpreter. I was so new to ASL that a lot of signs went over my head. Yet, when class was over, I realized I had gotten more out of that one class than I had all semester. That was an eye-opener, and after that I exposed myself to as much ASL as I could.)

Rachel Zemach was born hearing but lost her hearing at the age of 10. She learned ASL but struggled with how to define herself. Was she deaf, Deaf, hard of hearing, or hearing? She became a teacher, teaching first a Deaf class at a public elementary school in California, and then at a large Deaf school. *The Butterfly Cage* is about

“... the fantastic, flummoxing, and shocking years at both jobs. It’s about my personal transition from deaf to Deaf, culturally, but it’s also about the right of Deaf children to self-determination, and how the two schools approached this issue from radically different directions.”

Many of her stories will be familiar to anyone with hearing loss; she writes about missing fire drills because no one seemed to realize she wouldn’t hear the alarms, and about people not looking at her so she could see their faces and read their lips. This is not a book about inbetweeners. A short section at the back of the book lists tips for inbetweeners, including, but not limited to, joining organizations, and learning ASL.

If you want to understand why Deaf children finish their schooling unable to read or write at the levels their hearing peers do, or why Deaf children need an emphasis on language and not on speech, Rachel Zemach explains it well, probably the best I’ve read.

Rachel’s first teaching job was at a school that didn’t check her signing skills, and she discovered past teachers of the Deaf students didn’t sign. Almost everyone at the school, from the principal to the aides and therapists, expected her to lipread and be able to understand a public address system without assistance. They had even lower expectations of her students. She observes,

“Often the assumption is Deaf kids are limited in what they can do – or should be expected – to do.”

Yet, every time she set out to teach them things they weren’t expected to understand, from the meaning of various words to their home addresses, they became excited and took the concepts and ran with them.

One story that sticks with me is when Rachel’s sister met a Deaf woman and asked her, “Why don’t you and other Deaf people learn to talk?” The response was, “I can’t learn to hear, but you can learn to sign. So maybe the better question is, why don’t you sign?”

In an education system in which Deaf children are considered a “success” if they can talk, and their future abilities to read, write, and lead successful lives are ignored, the Deaf children can be browbeaten into depression, and even suicide. The public school district in which Rachel taught didn’t want their students moving to the nearby school for the Deaf, mostly because it would mean a loss of money to their district. But Rachel observed, for the few students who managed to transfer to the Deaf school, their outlook on their futures improved, and their life skills became comparable to the life skills of their hearing peers.

I sometimes wonder, when thinking about myself and my friend Judy, which of us got the better deal in life. Maybe the answer is six of one, and half a dozen of the other. How different our lives might have been if both of us had been exposed to ASL after our diagnoses, instead of pressuring us to learn to hear, an impossible task for both of us.

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

Linda Binns



I grew up with normal hearing. No issues at all, until I was 38, when my hearing began to deteriorate, due to a blow to the head, right over my right ear. First came the hearing aids, a series of them, each set more expensive and more powerful, as time went on. They helped somewhat, until they didn't. I had just married my childhood sweetheart, Andre' Binns. After a visit to the ENT, found out that my hearing had taken another big drop. I left the office and began to cry, at the elevator. The nurse came out to ask if I was okay. I said, "No, but I WILL BE." And I was. I went straight home, got online and found the SayWhatClub, and joined up (Arthur Veen from Holland was my HC

mentor). That was in late 1999. Whew. I immediately felt at home. These people already knew everything I was dealing with! World list was my new home.

Time went on. Talk began about Cochlear Implants. It was 2005.

I did the evaluation. I qualified, on my right side. I took a step back. I dithered, telling myself, "It's not that bad." It was. My hearing loss got worse. I was still working, only 50-ish and nowhere near retirement. I was working in San Diego, CA, as a Child Support Officer for the District Attorney, establishing and enforcing child support court orders. Lots of phones, and in-person meetings with clients, so very outward facing work. A year passed. Things got worse, and finally, I caved. I was so scared of the whole process. So many CI recipients go through this same psychological fear.

I tried to cancel the night before the surgery. Andre' told me, "You have nothing to lose." He was right. I had the surgery and stayed home for a week. My recovery was uneventful, and I continued to work during recovery. Finally, it was activation day. I was one of the lucky ones. Probably due to the fact that I am late deafened, and already understood speech and sounds, the CI worked flawlessly for me, right away. I was so excited, but I wanted to kick myself for dithering around for a year when I could have been hearing. I was getting SO much online support in the SayWhatClub, especially from long-term folks like Jazzy Wingert. I eventually qualified for the second CI and couldn't wait to go bilateral. I'm grateful for the technology and 21 years after I received my first CI, I'm doing very well.

I became an active volunteer for SWC, starting off as a List Rep, went on to join the Board of Directors (BOD) and became President. Very good time in my life, and I look back at the time fondly. Today I have the title of List Rep Chair. SWC is extremely important to me, and I attend most Cons, having only missed a couple. My friends here have become family. My now deceased husband, Andre' was warmly welcomed into the fold and he did some photography for the club, at the cons. I have no reason to think I won't be with SWC for the rest of my life, always grateful for the friendship and support, and hoping I am able to provide the same.

Safety First - Home Safety

Staying safe with hearing loss requires practical adjustments for your home, travel, and emergency readiness. Hearing is one of our primary senses when it comes to detecting danger. It helps us to response to alarms, sirens, footsteps, and spoken warnings.

Did you know that hearing loss increases your risk of falling. A 25-decibel loss can triple your chance of falling. Each additional 10-decibel hearing loss increases your chance of falling by 1.4 times.

- **Smoke and Carbon Monoxide Detectors:** Install specialized alarms that feature flashing strobe lights or powerful bed-shakers alongside extra-loud, properly-pitched sound alerts based on your hearing.
- **Fall Prevention:** Clear away loose throw rugs, reduce clutter, and add bright lighting or nightlights in all hallways and bathrooms.
- **Consistent Hearing Aid or Cochlear Use:** Wear your hearing aids regularly at home, which studies show can cut your risk of accidental falls in half by improving spatial awareness.
- **Keep those devices clean and charged:** Clean and charge your devices regularly. Keep spare batteries and power devices to use in the event of an emergency.

Editor's Letters by Deanne

I attended a Disaster Preparedness webinar from my local HLAA chapter and we went through a number of steps needed to prepare yourself in the event of an emergency. There are a number of Key Steps

Key Steps to Prepare

- **Know your risk** by learning which natural disasters or emergencies are most likely to happen in your local area.
- **Make a plan** with your household, including two meeting places, emergency contacts, and evacuation routes.
- **Build a kit** stocked with water (one gallon per person per day), non-perishable food, flashlights, and a first-aid kit to last at least 72 hours. You can purchase pre-made kits or make them yourself. Make sure to include your hearing supplies and batteries.
- **Documentation:** Include necessary paperwork, i.e., birth certificates, marriage certificates, driver licenses, tax returns, bank information, medical records and prescriptions, hearing aid/cochlear serial numbers, communication contacts and more
- **Stay informed** by signing up for local weather alerts and downloading the FEMA App for real-time safety notifications.
- **Get involved** in your community by learning first aid, CPR, or joining local volunteer safety groups

For more information. here are some helpful websites to check out.

[National Preparedness Ready Campaign](#)

[American Red Cross National Preparedness Month](#)

[United Way: United We Prepare](#)

[The Best Emergency Preparedness Supplies](#)

Send your comments to newsletter@saywhatclub.org. We are looking forward to hearing from you!....The Team

HEARING LOSS, part 3

Today's Hearing Loss articles will focus on one form of hearing loss: Otosclerosis. Carol Hansing and Bet Whitcomb are sharing their hearing loss journeys...

Carol's Journey

We had just moved to Memphis, TN, as my husband was changing his role in the United States Navy and going to a new school at NAS [Naval Air Station] Millington, TN. Our children were about 5 and 3 1/2, and we had moved for this school. My husband was anxious to start this new training. But he noticed I was having difficulty hearing him and said, "You don't have any problem hearing your lady friends."

We sought out help from Beltone Hearing Company, who advertised that they would come to your home and give you a hearing test. The hearing test consisted of the man standing behind me with me seated at the kitchen table, and him reading some words. Of course, he was a male with a low voice, and I had difficulty understanding the words.

My husband suggested I check into the NAS Memphis military hospital for some kind of assistance. There, I saw an ENT surgeon who diagnosed me immediately with otosclerosis and set up an appointment for surgery on my left ear. This was 1966, and he advised me I would be awake during the surgery, but high on medication. He didn't want me to move, as the surgery was delicate; there's a facial nerve that runs very close to the ear that, if sliced, would cause the opposite side of the face to droop.

During surgery the doctor went straight into the eardrum with a magnification 32 times the normal size of the stapes bone. He broke the stapes bone and replaced it with a piece of Teflon. To this day, I still carry that piece of Teflon in my ear. I spent the night in the hospital and went home the next day. The Dr told me not to turn my head fast nor to fly. I was resting at home, lying on the bed when a train (about a block from our mobile home) went by. It shook the mobile home so fiercely that I asked my husband to come and hold me down, as the top half of me was going one direction, and the bottom half was going the opposite direction. Not a good feeling. I got through that, and today that is the best of my two ears.

In 1992, I decided to have surgery on the right ear at Fitzsimmons Army Hospital, Denver, CO. Because I was sent to Fitzsimmons from a different hospital, I never really got to speak to the doctor and ask what prosthesis he would be using. He knew I flew in, so there was no hint of not flying, but I did spend the weekend there. In fact, the surgery wasn't that much help. Stapes surgery (stapedectomy/stapedotomy) is a highly successful 1-2 hour outpatient procedure to treat conductive hearing loss caused by otosclerosis by replacing a fixed stapes bone with a prosthesis. An incision is made in the skin of the ear canal, the skin and eardrum are lifted to expose the stapes bone, and the stapes bone is removed. A prosthesis is put in place of the stapes bone, and the eardrum and skin of the ear canal are laid back in place. A small amount of tissue is removed, often, but not always from above the ear. The tissue is used to cover the opening created by the stapes bone removal. In my first surgery a piece of vein from my wrist was used. I have no idea what was used for my second surgery. Recovery typically takes 4 weeks, with most returning to normal activity in about 1 week. Risks include dizziness, taste changes, or, rarely, worsened hearing.

After many years, my hearing was going bad again, and I started wearing hearing aids in 1998

Bet's Journey

Otosclerosis is a condition that affects the bones in the middle ear. Abnormal hardening of these bones, primarily the stapes, causes them not to vibrate properly. This in turn impedes the transmission of sounds to the inner ear. In its early stages otosclerosis causes purely a conductive loss and can be treated with hearing aids. Its effects can be somewhat corrected by a surgery known as a stapedectomy. In this surgery the stapes is removed and replaced with a tiny piston.

Until I joined SWC the only people I knew who had otosclerosis were in my family. My mother had this condition and passed it along to three of her children. While it does run in families, one theory is that its onset can be brought on by measles, a disease which we all had. My mother had been hard of hearing since her youth, but pinpointing otosclerosis as its cause never happened until she was nearly 60. Once she was diagnosed and learned that a relatively easy surgery called a stapedectomy could help, she was encouraged. She decided to undergo the surgery; the improvement in her hearing was dramatic. This weighed in my decision to undergo stapedectomies years later.

Otosclerosis worsens with pregnancies. In retrospect, I can trace the start of my hearing loss to my college years, but it was after the birth of our first child that the loss became undeniable. It worsened after the birth of our second child. She was 7 months old when I got my first pair of hearing aids, in the spring of 1984. At this point analog aids that merely amplified were sufficient for my needs. When our third child was born my hearing took another hit, slipping into the moderate and severe ranges. When he was two, I had my first stapedectomy in my left ear. Five years later I had my second in my right ear. Unlike Carol, my surgeries were under general anesthesia. Doctors had determined that the risk of a patient moving while under local anesthesia was too great, given the delicacy of the surgery.

While each surgery was successful in that my hearing did improve, I still needed hearing aids. After a few years the prosthesis in my left ear failed. I consulted two surgeons and each agreed that the risk of revision surgery was not worth the possible benefits. Then the hearing in my left ear took a precipitous drop and it was decided that revision surgery was worth the risk. This was done in 2016. Its benefits lasted for a few months, then this prosthesis also failed. Further surgery on the ear is not recommended.

Now, as I age, my hearing is no longer purely conductive but is a mixed loss that is in the severe to profound range across the board. As Carol pointed out, otosclerosis affects the low frequencies more; aging affects the high frequencies. So my audiogram looks like an upside-down speech banana, with profound loss at both the high and low ends, a severe loss in the middle frequencies. Since the middle frequencies, where I hear best, include mostly vowel sounds that can be spoken with more power than the consonants (see the speech banana), vowel sounds dominate what I hear. This can make decoding speech a true guessing game for me.

Update on the email lists: All lists should be referenced by [listname]@saywhatclub.org We have moved away from the Isoft distribution lists. Be sure to update your contact lists.

LEIONHearing

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AI-powered glasses
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AIS Impact Award 2025



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hard-of-hearing community.

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Pioneer Program



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25 Year Club Members

Please take a few minutes to reach out and congratulate our long term members

NAME	YEAR JOINED
Alan Sprague	1994
Alan Czarnek	1994
Brenda Dawe	1995
Neil Bauman	1996
Kate Johnston	1996
Robyn Carter	1996
Christine Seymour	1996
Larry Littleton	1996
Leslie Cotter	1996
Don Lampert	1997
Lori Peterson Hilliard	1997
Wendy Tirabassi Kast	1997
Marti Castor	1997
Donna Penman	1997
Arthur Veen	1998
Jim Gricci	1998
Barb Bavidio	1998
Melissa Jay Craig	1998
Diane Pease Fanuel	1999
Elaine Procida	1999
Lori Harville	1999
Martha Wilson	2000
Debbie Gilmer	2000
Linda Binns	2000
Scott Oberg	2000
Claudia Damian	2000
Patsi Schuhmann	2000
Ruth Ann Saunders	2000
Pearl Feder	2001
Lorne Smith	2001
Susan Steinerman	2001
Cynthia Maguire	2001
Kim Ward	2001

NOTE: if you have not yet received your certificate, please send an email to [Bet](#)

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.

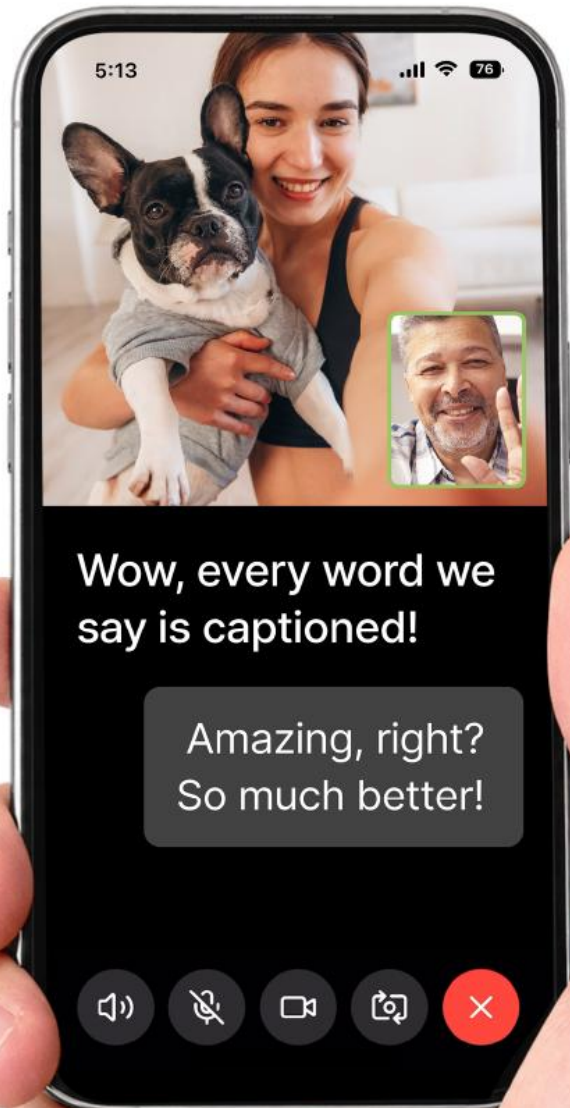


Making video calls more accessible

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!

-  **Fast, accurate captions**
-  **Always onscreen**
-  **Call anyone, anywhere**
-  **No cost to users**

Download the app



FEDERAL LAW PROHIBITS ANYONE BUT REGISTERED USERS WITH HEARING LOSS FROM USING INTERNET PROTOCOL (IP) CAPTIONED TELEPHONES WITH THE CAPTIONS TURNED ON. IP captioned telephone service may use a live operator. The operator generates captions of what the other party to the call says. These captions are then sent to your phone. There is a cost for each minute of captions generated, paid from a federally administered fund.



Coming in November - Fall Fundraiser

November is the month when we reflect and think about the all the things we are thankful for. If the SayWhatClub has made a difference in your life, please consider making a donation during our Fundraising month to help support our work towards hearing loss awareness.

This year's goal is \$4,000, any amount is appreciated. The Fundraiser runs from November 1-22. All monies donated go to the club expenses.

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.

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

Board of Directors

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

Final Call....we need 10 more to place an order.
Order shirts here: [T-Shirt order form](#)

Prices are:

\$30	Short-sleeved tees, crew or V-neck
\$33	Short-sleeved XXL
\$35	Long-sleeved tees
\$38	Long-sleeved XXL
\$60	Hoodies
\$65	XXL Hoodies
\$70	Zipper Hoodie
\$75	XXL Zipper Hoodie

Prices include all fees and shipping costs.

Orders must be submitted by the end of October.
Shirts will be shipped directly.



Do you need 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 |
| • CI | Judy Heimbach, Linda Binns |
| • Explore | Martha Wilson |
| • Forum | Bet Lareau Whitcomb, Carol Hansing |
| • 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, making sure that the conversation on the list flows and resolving any disputes that may arise. Contact Linda Binns for more information