

HEARING LOSS HERALD

ALDA-MAINE Educates, Advocates, offers Role models, and Supports for and about hearing loss, especially for deafened and hard of hearing adults and their communities.

Now Hear This!

A Letter from the
Editor

Spring is happen-

ing outside my window and it's a big distraction when I am trying to write my "piece" for the Hearing Loss Herald! But whatever, I'm excited to bring this new issue to you, there's a ton of good information and new things to think about.



The reality of having a hearing loss in this day and age is that there is always something new to learn. For example, do you know what **CART** is? Ever heard of **Cap-Tel**? Did you know that **COAT** is looking out for your interests in a handful of different ways? Do you know how many Mainers have a significant hearing loss but don't use sign language? (I'm not telling, you must read it for yourself) Do you know why deafened and hard of hearing folks in Maine have very few services directed to their specific needs? Do you know what age group has the greatest need of help with hearing aid purchases?

All this and more is only a page turn away. Be sure to read every word and then pass your issue on to someone else who needs to know!

Juen

THE LITTLE TOWN THAT COULD AND DID!

By Michie Stovall O'Day

As a late deafened adult, who has marginal ASL skills at best, I have not been able to participate on Stonington Town Meetings since I moved here in 2000. After recent success asking my doctors at Mass Gen Hospital in Boston to provide CART for me (where they are so pleased with it that they are now offering it to other deaf patients) I decided to give it a try here at home.

In early December I attended a weekly Selectboard meeting here in Stonington to tell the board members about CART, explain the benefits and request it for the annual Town Meeting in March. I also gave them written materials about CART and the name of a good CART interpreter that I have worked with before, Shari Majeski, www.maineart.com

Fortunately, we have a new Town Manager, Kathleen Billings-Pezaris, who is from the area and deeply committed to helping citizens participate in their local government. She is highly capable and her can-do attitude is infectious. The Selectboard

gave their nod of approval to my request, and the new Town Manager quickly became an expert on PA systems, speaker phones, laptops and all necessary equipment and connections for CART. She and her husband were in the meeting room on their own time setting up all the equipment for Remote CART, testing to make sure it all worked, and practicing with the 2 interpreters who did the 4 hour Town Meeting pm March 3, 2008. They deserve all the credit. All I had to do was ask for this wonderful and reasonable accommodation for my disability.



As is often the case, I am not the

only person who benefits from such accommodations. This year's meeting was the first time a PA system had been used, and it was the first time that people said they could hear. The need for such a system in a large room would seem obvious, but often it is not obvi-

ous to people with normal hearing. We passed the microphone around to each person who spoke, for the benefit of the CART interpreters who were both working from their home offices in different states, but everyone benefited from the amplification. The captioned text was projected on a large wall over the Selectboard's table in front, so that anyone who needed to could see it and refer to it if they missed something in the meeting.

CART has the added benefit of providing a written transcript of the meeting which Town staff and government can opt to acquire if they choose and refer to afterwards as needed. It is a win-win arrangement for all involved, and I am delighted that a town as small as Stonington responded so positively to my request, although it really should come as no surprise. There are a lot of friendly and helpful people in our community. When asked politely and professionally to provide this accommodation, the natural response was yes. **Bravo Stonington!**

Sprint, Caption First, Harris Communications, Hamilton Relay, and Maine Center on Deafness for advertising support in the *Hearing Loss Herald*!

Sandra and Amy for planning the April ALDA Maine/MCD meeting in Augusta

A special thanks to **Amy** for sharing her expertise about legal matters, advocacy and civil rights for people with hearing loss.

Amber's grandmother for her support

Thank You!

Edna for her terrific computer skills

Amber for working on HLH with Lauren & Gwen

Gerry for helping to distribute the HLH to senior citizens in Bangor

Eric Conrad, for publishing the story of *Hearing Loss Herald* in the Kennebec Journal and Morning Sentinel.

Rod and other voices rejoining our online forum

All the authors of articles in this issue of HLH

Lauren thanks her husband **John** for so much support to plan, begin and carry on with our ALDA-Maine Chapter!

Ann Smith, Shari, Sandra, & OJ for efforts in making personal captioning available at UM graduation

Shari Majeski and MaineCART for so many services and support.

Technology Center at UM Augusta for meeting space for our April Meeting

The President's Corner

Welcome readers!

If you are "hearing" or have a hearing loss, we invite you all to join the fight!

What sort of fight? One that is filled with love, concern, and passion for the civil rights and needs of all people who struggle to remain involved, contributing, active and healthy citizens, in spite of sudden or gradual hearing loss.

Why a fight? Because established ways (government, organizations of any good size, some people and many groups) are like huge elephants – they do not move unless you give them a humungous push. They are adorable and good, yet there are real, urgent, and vital needs among thousands of people with hearing loss. We'd rather communicate and collaborate, instead of initiate legal action, and when that is needed, we are prepared to do that too.

How is our fight different? We help ourselves, a lot! We "fight" by finding ways together to deal with a lot of stigma and hurtful comments from others; by coping with misunderstanding (see conundrum below); by making time and finding energy, each day, to survive in a world where hearing loss is so confusing to others, even to our families and friends.

Sometimes we need new friends, and sometimes we need new career opportunities. Mostly, we don't need

pity. We need resources, and time from others to understand and learn along with us, and to help us get these resources.

We are deafened or hard of hearing, yet we are not dumb, daft, nor diminished. We share with you. We offer information, and encourage communications via any medium available (email, this publication, a members' forum online, captioning for a group meeting in person, whatever works!, because our ears no longer work well.

ALDA-Maine members have benefits in addition to the newsletter. As a relatively new official non-profit, we'd like you to become a member (only ten dollars annually). Even as a visitor, guest, sponsor, or supporter in other ways, we need you, and await your message of interest. Hearing loss affects one in three to ten people, depending on your age group, everywhere! It "happens" to young and older. If you are lucky to live a long life, chances of hearing loss are higher.

As we write this in advance of publication, there's an important news story from the AP about the high occurrence of severe hearing loss in soldiers returning home from wars. They, and all of us, deserve the best resources, information, equipment, time, care, and support. Join the fight here at home with us. ALDA-Maine hopes to hear from you, for yourself and friends, and for over

100,000 others (low estimate) with hearing loss in Maine, Vermont, and New Hampshire (and over 31 million across the USA).

Here's the first in a series of "closing conundrums" that I'll try to use in each column. Comments invited.



Someone says, smiling, "You mean you're selectively deaf, right?"

We might say, "How we wish!" We know it's meant well. How to respond? When hearing diminishes (each of us with a different pattern of loss across all sound frequencies), some continue to hear some voices, some of the time, depending on the other person's voice and the situation. Hearing a voice or noise, however, is different from understanding (speech comprehension), and comprehension uses much extra energy each day.

Take time to smell spring flowers everyone, and if you are able, to hear the birds!

Aldabest,

Lauren

Lauren E. Storck, Ph.D., Advocate for Accessibility Equality, President of ALDA-Maine





Television stations in Maine and around the country are preparing for the day

they will have to turn off their analog transmitter, leaving only a digital transmitter to broadcast their programming offerings. That day is February 17, 2009. Are you ready for this change? How does this affect you?

From the remote control to home video recorders to closed captioning to large flat screen televisions, change has steadily occurred. The next change is arguably the most important, because some viewers could potentially lose their local TV signals.

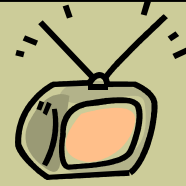
Most television stations are broadcasting both Analog and Digital transmissions. WCSH 6 and WLBZ 2 began Digital broadcasts in May of 2002. If someone purchased a Digital television and hooked it up to an antenna, they would be receiving 2 different channels. They'd see the regular or main channel on channel 6.1 in the Portland area or 2.1 in the Bangor area and a 24/7 weather channel called NEWS CENTER Weather Plus on channel 6.2 or 2.2. An advantage that Digital television has is the ability to broadcast more than one channel at a time. Another advantage is high definition TV (HDTV). Stations can pass through national programming, such as sports or primetime programs in the 16x9 ratio in HDTV giving the viewer a "watching a movie" in a theater feeling.

How you receive your television signal affects what you need to do to continue receiving local television programs. If you use an antenna without a new Digital television and without cable or satellite service, you will need to take some action. If you have cable or satellite service on all your television sets, you will not. For those people using an antenna with an Analog television set, you will have to acquire a Digital Converter Box. This Converter Box will act as your channel selector as the one on your Analog television will no longer work. If you are a closed caption user, you will be able to receive closed captioning through the converter box. The Federal Government has made available coupons valued at \$40 to go to purchase a Converter Box. This government approved Converter Box will cost between \$50 and \$70. Using the coupon will bring the cost to consumers down to \$10 to \$30 dollars each. Each household can get a maximum of two \$40 coupons, each good for buying one Converter Box (you cannot use both coupons to buy only one Converter Box). You can apply for the Digital Converter Box coupons by calling 1 888-DTV-2009 or online at <http://www.ntia.doc.gov/dtvcoupon/index.html>.

If you or someone you know relies on an antenna to receive

Are you ready for the Digital Television Transition?

By Mike Marshall



their local television stations, take action immediately. Don't wait. The coupon program will most likely run out of the available coupons by

the end of 2008. The sooner you take action, the sooner you will begin to see a sharper image and a second channel from stations that have them. If you have any questions about the Digital Television Transition you can contact mike.marshall@wscsh6.com or call 1-800-464-1213 and ask for ext. 214. Thank you.

Mike Marshall is the Vice President of Programming and Marketing for WCSH 6 and WLBZ 2.

Submissions and advertisements for the Summer (August) issue of Hearing Loss Herald are invited and due on July 1, 2008. Send to glapointe@aol.com. Inclusion and/or editing will be at the full discretion of the Editor.

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WE ARE BANKING ON YOU

By Warren Center Audiologists Dr. Amanda Samoluk, CCC-A & Dr. Kim Starkey, CCC-A



The Regional Hearing Aid Bank program (ReHAB) is funded through donations and grants but as the program has grown, the number of requests has grown as well. We now have an unprecedented number of residents waiting to receive hearing aids.

The program began seven years ago when the Warren Center for Communication & Learning in Bangor received a letter that said, "My friend has a heart condition and cannot hear. He cannot afford to buy hearing aids and does not qualify for the Vocational Rehabilitation program because he cannot work due to illness. He cannot understand what the doctor is saying and is misinterpreting medication instructions. What can be done?" This letter, paraphrased here, is the reason the Regional Hearing Aid Bank exists today. There was a need, and we believed it needed to be filled.

The Regional Hearing Aid Bank program, better known as ReHAB, is a program that provides reconditioned hearing aids to qualified Mainers at no charge to them. Those who participate in the program, and can afford it are asked to contribute between \$2 and \$25 dollars. Hearing aids are one of those items which are not traditionally covered by health insurance and must be purchased out of pocket.

Why should we care? We should care because hearing loss in adults is one of the biggest reasons these folks tend to isolate themselves. It happens slowly over time. People do not realize they have lost hearing; but they begin to stop attending social events, church, going to restaurants. It is very frustrating to keep saying what and not knowing why you cannot hear your grandchild or a concert. This in turn causes isolation, and isolation in adults is a

major cause of depression. By providing a hearing aid we are making sure that Maine residents stay connected to families and communities.

This important program has grown over the years. We receive donated hearing aids from across the state, and we receive requests for hearing aids from Fort Kent to South Portland to Calais. We have over 103 people on our list. At our current rate of funding hearing aids this means a wait of over 5 years. It costs \$500 dollars to recondition, fit and warranty a hearing aid. Which might sound like a lot of money but the cost of purchasing a new one is between \$800 and \$4,000 per ear. Reconditioned aids provide a needed service.

In order for us to provide each person on our waiting list today with a hearing aid it would cost **\$51,000**. Everyday our list continues to grow and everyday an adult resident in

Maine is waiting to be able to hear the birds of spring, and their friends at a bake bean supper saying, "Did you hear about...?" Please help us, help your neighbor.

The Warren Center for Communication and Learning is a non-profit agency dedicated to helping people of all ages overcome barriers to effective communication. Monetary donations for the ReHAB program can be sent to the Warren Center, 175 Union Street, Bangor, Maine 04401

ReHAB Applicants by Age March 2002 to March 2008

age	number	percent
80+	84	30%
71-80	81	29%
61-70	56	20%
51-60	37	13%
<50	23	8%

Defining Your Hearing Loss: Part II of A Three Part Series

In the February issue of HLH we discussed three types of hearing loss: Conductive, Sensorineural, and Mixed. We continue this series about defining your hearing loss by using a short and sweet chart that describes the Degree of Hearing Loss.

Normal range	0 dB to 20 dB
Mild loss	20 dB to 40 dB
Moderate loss	40 dB to 60 dB
Severe loss	60 dB to 80 dB
Profound loss	80 dB or more

Degree of hearing loss refers to the severity of the loss. There are five broad categories that are typically used. The numbers represent the patient's **thresholds**, or the softest sound that can be perceived. **dB** stands for **decibels**, which in this instance is a measurement of sound levels compared to the softest sounds that can be heard by a human ear. When you have a hearing test, the audiologist will record different measurements on an **audiogram**. Your **thresholds** will be one of the measurements on your audiogram.

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Hello –

I thought as first time user of the Cap Tel phone, that I would share some of my experiences with you, and give some basic guidance as to how Cap Tel works. I have to admit when I first opened the package and saw a 52 page manual in the box, that I procrastinated for quite some time! However, once I unpacked the phone and began to read the manual, along with some helpful newsletters, everything went fine. Now for some of the details:

First, the phone itself is really nice. The most important distinction between Cap Tel and a regular phone is a large display screen at the top of the phone. The screen is easy to read, similar to a

The Cap Tel Diaries

By Randy Schwartz

black and white TV screen, with adjustable contrast levels. The screen is 4" wide and 2" long.

The phone pad consists of extra large number buttons. Also very importantly, there are multiple options for controlling tone and volume. There is also a ringer control, various lights, and a headset and audio jack. A review of the manual (which is well written and easy to follow) will provide valuable information and tips.

Once you've familiarized yourself with it, just plug it in and connect the jack – and that it is. However, don't make any calls quite just yet until you've

processed one very important step – register your long distance carrier(s) with the relay service!

The reason for this is that until you register your numbers with the service, they have no way of knowing the name of your interstate and intrastate carriers and will, by default, use the standard carrier (which varies by state). Their rates may be much higher than your own. Your plan might be 5 cents per minute while the default rate might be 40 cents per minute, so your phone bill might contain some unpleasant surprises if you fail to process this one step early on.

It is very easy to do – you can a) call a toll free number b) send an e-mail, c) register on their web site, or d) send a

(Continued on page 7)

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ALDA Maine is a 501 (c) (3) non-profit. Donations are tax deductible.

(CAPTEL, Continued from page 6)



letter by regular mail. I found customer service to be excellent for all Cap Tel related issues. Once this step is processed and confirmed, you are good to go!

As to using the phone: each person will find varying degrees of efficiency and satisfaction. It all depends on your hearing loss and how you choose to utilize the captions. For example, someone who has just a 20% hearing loss will find it vastly different than someone who has an 80% hearing loss. With a less severe loss, there will be much more of a tendency to utilize our hearing - and only use the captions as a backup. With a more severe loss, there will be much more of a tendency to use the captions - with the listening component as a backup. As noted earlier, there are multiple volume control options to supplement the captions. There is a volume booster, volume control, and tone control on the phone. There is the option to add other volume controls. Finally, of course, there are the telephone coils on our hearing aids. One must determine for themselves the right combination that works for them.

My own personal hearing loss is such that I use all of these options in combination with each other, adjusting as needed to the particular call. I use the captions, volume booster in the "on" position, volume control at mid-level, tone control to bring in the deeper tones, an add-on Walker volume control, and my hearing aid telecoil "on" at medium. That combination, for me, works as well as can be expected for someone with a severe hearing loss.

Once you set it up, call up a friend or relative. Try it with them and see how it goes. Later on, try a business call or two and see how that works. Before you know it, you will find your own comfort zone and will find Cap Tel really helpful, varying by individual needs and hearing loss.

As to the captions themselves, it takes a few seconds to connect. Once connected, the Communication Assistant (CA) relays word for word what the speaker is saying. Several seconds later (it can vary) the words appear on your screen! There are a number of symbols and words that will require getting used to. For example, the caption might read <music> meaning that music is playing in the background. Quite frequently, you will see <speaker unclear> meaning the CA could not understand the speaker. There are quite a few of these parenthesized items that you will have to get used to. They are outlined in one of the newsletters.

With Cap Tel, the CA is always in the background and not involved in the conversation (unlike a TTY operator).

Finally, one key decision you will have to make once you're set up and using your Cap Tel: Should I - or should I not tell the other speaker that I am using Cap Tel?


The answer: that is entirely up to you. Either option is fine! For some callers you may wish to tell them ahead of time; for others, you may choose not to. However, since there is a delay of sometimes up to 10 seconds, the gaps can admittedly become awkward as you wait for the captions to appear and your caller wonders why it is taking so long to respond. There ends up being a lot of "mm-m-ms" and "uh-h-h-hs." Therefore, on balance, it is better to inform your caller that you have a hearing impairment, are using an assistive device, and to please bear with you. Almost universally, they will understand.

Finally the one line versus the two line option: In a nutshell, the two line option, while better, is also more expensive (like anything else!). I have the one line option and for me it is just fine. There are several differences (some of which involve "911" issues) which I will discuss in a future issue of The Hearing Loss Herald!

In the meantime, if you have any questions about this article or need more information on my experience with the Cap Tel, please feel free to e-mail me; I will be glad to help!

Randy

randy626364@yahoo.com




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ALDA-MAINE IN ACTION

A CALL FOR VOLUNTEERS



ALDA Maine and Maine Center on Deafness joined forces once again in a meeting in Augusta on the evening of April 24th to discuss accessibility and funding for accommodations for late deafened and hard of hearing people. Those of us with hearing loss who do not use sign language do not benefit from sign language interpreters, which is often the only accommodation that is offered when communication issues arise. Other accommodations, such as CART(captioning) and/or FM listening systems would be more appropriate, but they are not well known or easily obtained and there are fewer public funds to provide them.

Amy Sneirson, from Maine Center on Deafness gave a summary of the legislative process and explained the means by which the culturally Deaf in our state have learned to advocate for their accessibility needs in a way that has brought their needs into focus. The late deafened and hard of hearing citizens of our state, whom make up 90% of the people with significant hearing loss do not have this high visibility and their needs are just as important for communications access yet are lesser known. Says Sneirsen, " Most folks who are hard of hearing or late deafened have been raised in an oral environment, and most of you speak just like everybody else. And you're indistinguishable to most people from the hearing world. And they don't realize that you don't, that you can't hear them, and I think it is human nature in most situations to just nod and get what you can out of it. Asking for accommodations is something that most of us are not used to."

Drawing from the experiences of the culturally Deaf community, Sneirsen suggests two things that would help with accessibility issues for the late deafened and hard of hearing citizens of Maine. First, to develop a strong community among those who are late deafened and hard of hearing, which is a task that ALDA Maine has set for itself. And second, for that community and the individuals in the community to learn to advocate for themselves and harness the political power which has the voices of 110,000 hard of hearing and deafened individuals behind it.

This meeting is the second of a series of meetings planned jointly by ALDA Maine and Maine Center on Deafness to address the issues of accessibility and advocacy for the 110,000 hard of hearing and late deafened people who call Maine home. More meetings will follow in the near future and CART and remote CART (for those who cannot attend in person) are provided. All are welcome at these meetings and your voices are needed. What do YOU need to fully participate in your community life? Please let us hear about it!

Volunteers (hearing people too) are urgently needed to work on a draft of new legislation to address the needs of deafened and hard of hearing Mainers. One proposal is to seek support for adding funding to current established mandates from the Maine Legislature for "equipment and advocacy" programs (an annual contract awarded to a qualified agency). The goal would be to ask for additional mandated funding to focus on vital captioning resources for all. Contact us via email, aldamaine@gmail.com.

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COME ALONG AND GET YOUR COAT ON!

BY AMBER WILHELM



The Coalition of Organizations for Accessible Technology (COAT) was created in March of 2007 and has over 180 national, regional, and community-based organizations as members. (Editor's

Note: ALDA Maine is, at this writing, the only Maine organization affiliated with COAT.) **COAT's** purpose is to advocate for

"It is critical for consumers with hearing loss to become active, and alert their law-makers about the need to bring present laws on telecommunications and video programming access up to date. Unless we remain vigilant, the existing laws will continue to become outdated and the technologies that these consumers now enjoy will become inaccessible as they evolve."

Karen Peltz Strauss, COAT

provided over the *internet*.

With this in mind, COAT proposed a legislative draft (not yet a bill) called the **"21st Century Communications and Video Programming Accessibility Act of 2007"**.

Democratic Congressman Edward Markey of Massachusetts, who is chairman of the Subcommittee on Telecommunications and the Internet of the House Energy and Commerce Commit-

tee, released this draft to Congress in 2007 and is working with COAT to bring disability safeguards into the next century. This draft proposes:

Hearing Aid Compatibility-making sure people with hearing loss have access to telephone devices used with advanced technology

Relay Services-telecommunications relay services (TRS) must ensure that people who have hearing and speech disabilities can use relay services to engage in conversations with all other people, not just people without a hearing or speech disability.

Access to Internet-Based Services and Equipment-requires telecommunication, VoIP providers and manufacturers, and Internet-based technologies to make their services, equipment, and networks accessible; real-time text support must ensure people with disabilities are able to communicate via text in an IP environment as well as if they were using the public telephone network.

Universal Service-recognizes consumers with disabilities as a distinct group and eligible to receive universal service support through specific measure.

Closed Captioning Decoder and Video Description Capability-expands the scope of devices that must display closed captions under the Television Decoder Circuitry Act of 1990 from all 13 inches or larger TV's to all video devices that receive or display video programming

transmitted simultaneously with sound.

Video Description and

Closed Captioning-ensure continued accessibility of video programming to people with disabilities as this programming migrates to the Internet

User Interfaces-requires devices used to receive or display video programming, including devices used to receive and display Internet-based video programming, to be accessible by people with disabilities so that such individuals are able to access all functions of such devices (such as turning these devices on and off, controlling volume and select programming)

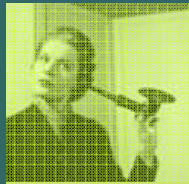
Access Video Programming Guides and Menus-requires multichannel video programming distributors to make their navigational programming guides accessible to people who cannot read the visual display.

To view a detailed version of this report, http://markey.house.gov/docs/telecomm/draft_of_telecom_legislation.pdf . If your organization would like to become a member of **COAT**, send an email with the name of your organization and a contact person to: info@coataccess.org. or visit the COAT website at www.COATaccess.org. In addition, write your congressional representative to support this legislative measure. This act is crucial to ensuring accessibility to those who have a hearing loss. So, come along and get your **COAT** on!



Ralph feared his wife wasn't hearing as well as she used to and he thought she might need a hearing aid. Not quite sure how to approach her, he called the family Doctor to discuss the problem. The Doctor told him there is a simple informal test the husband could perform to give the Doctor a better idea about her hearing loss. Here's what you do," said the Doctor, "stand about 40 feet away from her, and in a normal conversational speaking tone see if she hears you. If not, go to 30 feet, then 20 feet, and so on until you get a response."

That evening, the wife is in the kitchen cooking dinner, and Ralph was in the den. He says to himself, "I'm about 40 feet away, let's see what happens." Then in a normal tone he asks, "Honey, what's for dinner?" No response. So Ralph moves closer to the kitchen, about 30 feet from his wife and repeats, "Honey, what's for dinner?" Still no response. Next he moves into the dining room where he is about 20 feet from his wife and asks, "Honey, what's for dinner?" Again he gets no response. So, he walks up to the kitchen door, about 10 feet away. "Honey, what's for dinner?" Again there is no response. So he walks right up behind her. "Honey, what's for dinner?" "Ralph, for the FIFTH time, CHICKEN!"



Return to:
ALDA Maine
246 North Shore Rd
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04853

THE HEARING LOSS HERALD

HEARING LOSS ON THE WEB A GUIDE TO ONLINE RESOURCES

ALDA Maine Website www.alda-maine.mysite.com	ALDA Maine Keep up with ALDA Maine happenings and learn about our organization
Association of Late Deafened Adults, Inc. http://www.alda.org/	ALDA, Inc is our parent Organization, based in Chicago. Learn about the ALDA organization, join online chats, buy from the ALDA store.
Warren Center for Communication & Learning www.warrencenter.org	Warren Center Learn about the services and programs of this local not-for-profit organization
www.Maine.gov/legis/lawlib/billpath.htm	Learn about the Maine Legislative Process
League for the Hard of Hearing www.lhh.org/about_hearing_loss/living_with_hearing_loss.pdf	Helpful pamphlet on living with a hearing loss by the League for the Hard of Hearing

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