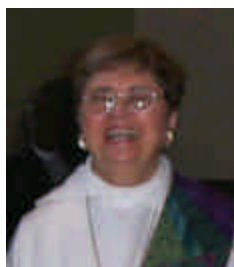


ALDA-GS News

Spring 2007



PRESIDENT'S CORNER

Spring greetings to all. We celebrated springtime and ourselves with our Twelfth Birthday Party on April 28th at the East Brunswick Library. CART, interpreters and Assistive devices were provided courtesy of DDHH. Lunch and two birthday cakes were provided by ALDA-GS. We could not fit the inscribed "Happy Twelfth Birthday ALDA Garden State" on one cake, so each cake bore half the greeting! Go to

page 12 for photos of this event.

We were fortunate to have Craig Barth, M.A.,CCC-A, FAAA, as our guest speaker. His presentation of "Benchmarks for Successful Hearing Aid Fittings" was extremely well prepared and followed the handout he had created for us. Craig has long been my audiologist and also for many of the attending guests. Craig will provide copies of his talk to anyone interested. Go to CTB1954@aol.com

Twenty-six guests enjoyed the information, lunch and fellowship. Among them was our new Vice President, Debra Erickson. It was a pleasure to have her on "board".

. . Our listserv, ALDA-GS@yahoogroups.com is open to all members and others who may be affected by hearing loss to chat and to share ideas and concerns. Many personal concerns about hearing loss are expressed and other members reply from their own experience. We welcome two new young participants, Kym and Elizabeth, to the listserv.

One current topic on the listserv has been Hearing Ear dogs. The questions ranged from "If there is a family dog already, can a Hearing Ear dog join the family, and still do the necessary job?" to how to find a good provider, and how to train your own dog. This developed into such an interesting discussion, we are considering it for our Fall Workshop topic. **I am interested in your opinion of that idea or any other topics you would like to suggest for the Fall Workshop.**

Recent donations were made to the East Brunswick Library and to The Paper Mill Playhouse for their support of ALDA-GS. As many of you know The Paper Mill Playhouse is in serious financial trouble and may be closed unless that can be solved. They have provided CART and interpreters for their performances on a regular schedule and their efforts should be recognized.

The Scholarship Committee is currently considering applications and that award will be announced in late May.

As always, I welcome your suggestions and concerns and hope you will share them. My contact information can always be found on page 2.

I want to give special thanks to everyone who helped make the birthday party the success that it was by bringing food and helping with set-up and clean-up..

Peace.
Sheila Shuford

ALDA-GS
Association of Late-Deafened Adults-
Garden State

President: Sheila Shuford

973-927-5554 CapTel scshuford@optonline.net

Past President: Eileen Hollywood

732-842-4430 TTY eileena2@aol.com

Vice President: Debbie Erickson

201-529-1608V deberick@aol.com

Treasurer: Diana Fanuel

aldafann@hotmail.com

Secretary: Cynthia Amerman

301-942-2454 V/TTY bigred0822@aol.com

Editor:

Elinore Bullock

elinorebullock7@earthlink.net

908-832-5083 CapTel

We welcome advertisements, articles, and information.

E-mailed articles preferred, no faxes please.

Other submissions must be clearly written or typed double-spaced and sent to:

Editor, ALDA-GS

3 Tamarack Farm Lane,

Califon, NJ 07830-3415

Calendar

May 20, 2007

ALDA-NJ Social

2 PM

To be held at the home of
Jeff Coppolo, Saddle Brook

Contact: Elinore Bullock
elinorebullock7@earthlink.net
908-832-5083 CapTel

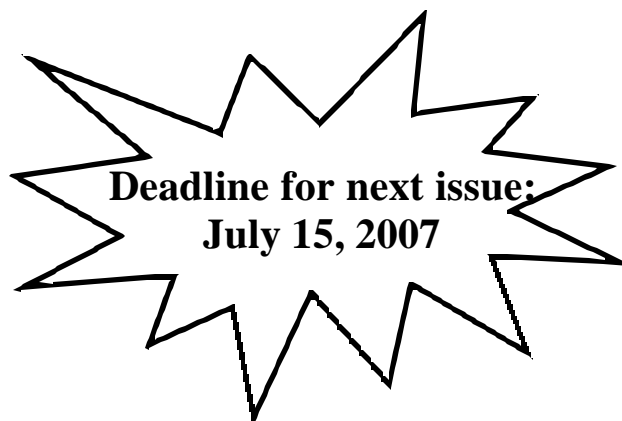
July 29, 2007

ALDA-NJ SOCIAL

1 PM (earlier than usual to allow ample swim time)

Pool Party at the Bullock home,
Califon, NJ

Contact: Elinore Bullock



Listserv Address:

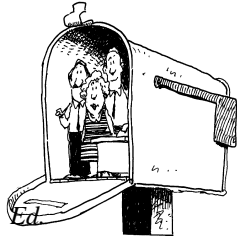
Come and see what all the buzz is these days!

<http://groups.yahoo.com/group/ALDA-GS>

Visit our Website:

<http://www.alda-gs.org>

The opinions expressed in this newsletter are not necessarily those of the organization. Each article has been written from an individual member's viewpoint.



LETTERS TO THE EDITOR

Note: Judy Ginsberg sent the below message to our listserv in response to a question regarding coping with hearing loss. I wanted to be sure that everyone sees it.

Kym,

There is a woman who trains hearing dogs in Vineland, NJ. Her name is Debra Schaser-Graef. Her website is <http://www.hometown.aol.com/chcheardog/index.html> Her email address is CHCHHEarDog@aol.com and her phone number is 856-696-3668

For an alarm clock the Ameriphone Notification system is the one I prefer. You can order it on-line with <http://www.harriscomm.com/catalog/default.php?webstore=main>

I recommend it because it is a combination of things. When the alarm clocks goes off – it will vibrate and I have a flashing light so there is no way you can oversleep. It will alert me when my telephone rings, or if someone rings my door bell, or if my fire or carbon monoxide alarms goes off. I'd rather have all these features in one unit. I purchased the combo unit so I have a remote receiver in my living room. This remote receiver is attached to my lamp with a very strong light bulb. So I am able to know when all the above sounds go off throughout my house.

You mentioned you have purchased a tty. I assume you have a certain amount of time to return it if you are not happy. I second Arlene Romoff's suggestion to try the CapTel phone. This way you will be able to chat with your friends and family and be able to read what they say.

Do go to <http://www.captionedtelephone.com/> and read all about it.

Access Features for National Park Service

Have you ever visited a national park? Would you like to do so? Would you like to be assured that the parks are accessible to you, AND your great grandchildren? Then take a few minutes to provide feedback to the National Park Service, so they know how to make the parks more accessible to you.

The National Park Service will celebrate it's centennial in 2016, and is initiating a nationwide campaign to listen to the public about the future of the parks.

It is imperative that persons with hearing, visual, cognitive, and mobility disabilities express their concerns and ideas about programmatic and physical access at National Park Service areas.

Send an e-mail to 2016@nps.gov to make suggestions.

Although the Park Service ran a web survey for this purpose, it is no longer active. However, they stress that they are always interested in hearing suggestions and provided the above e-mail address for those who missed taking the survey.

(Ed. Note: In connection with the above, Jason Weiland, of the DDHH wrote:)(condensed)

I called my National Parks contact. When I went to Ellis Island, ASL interpretation was not available.

A complaint was filed by the Bergen County Deaf Seniors group several years ago. They requested and were denied ASL interpreted tours with the National Parks Ranger. As a result of their advocacy efforts, they were successful in their complaint and reimbursed for bringing their own interpreters. It was mandated that ASL interpretation be provided at not only Ellis Island but also Liberty Island (Statue of Liberty). This is why you see ASL interpreted information on the website as a result of the settlement.

ISOLATION

By Michele Bornert

(reprinted with permission from ALDA, Inc.)

The word alone seems to create this overwhelming feeling of doom, doesn't it? Webster defines isolation as a noun meaning, "the state of being set apart from others; seclusion." Yep, that about sums it up. If there was one feeling I experienced when I became deaf, it was definitely isolation. No longer hearing yet not culturally Deaf. You know the scene. And, of course, if you're not "deaf" but hard of hearing, that only intensifies the feeling. Not 100% comfortable among those with no hearing loss but still have enough residual hearing to use the tools of the 'hearie' such as the telephone and an occasional yet frustrating, uncaptioned movie.

I have to say that, in some ways, I had it easy. I mean, when I became deaf, everything went. Couldn't even hear myself scream if I tried (and believe me I did... often). There was no question of whether I had "enough" hearing or a "substantial" hearing loss, and all that other jargon they throw at you to make them sound like they know what they're talking about. So when the subject of identity came up, at least I knew where I did *not* fit in.

But isolation is not only a whole different ballgame; it's a whole different sport! A three-man sport, if you will, involving you, you and... uh... you! If you look close enough, it involves pretty much everyone you encounter in your daily life. How so?

Well, think about it. You're at work. You become parched. So you get up and approach the water cooler. Around it is the usual clique dishing out the daily droll of gossip and complaints. As you get closer, you give your most sincere smile—a smile that's a cross between Carol Channing and the Crest toothpaste model. The people in the group notice you coming their way; their eyes widen as they glance amongst themselves and try to emulate your enthusiastic grin. Then, quicker than you can adjust your hearing aid to meet the room's needs, every one of them runs for the hills (and if they can't find one, they'll improvise, I assure you). You're left alone with a cup of water and a vague feeling that you might need to switch deodorants if you want to keep your friends.

Or how about when you're at home. You're taking care of the litter and you think you see the phone signaler flashing. You look at it but then you blink and you're not sure if maybe it flashed when you blinked and you missed it. So you stand there with your eyes glued to the light. Your eyes become so dry that they start to water but you're determined to keep them open long enough to make sure that that light isn't flashing. Just then you see it flash! Yes! You were right! You run for your TTY or amplified telephone only to be five seconds too late. But don't you fear. They'll call back. And when they do... "Did I just see that light flash?" It starts all over. You spend your days completely paranoid because you just don't have enough signalers around the house. Some days you wonder why no one ever calls anymore. Other days you wonder if there's a special kind of tape you can buy to keep yourself from blinking during the day.

How about your partner's company party? You're dressed up to the nines. You and your significant other sashay into the room. Your partner wants to introduce you to his boss so you both approach the small circle of people drinking champagne and laughing politely at everything this man, who has a beard that would make Santa Claus look like he has a five o'clock shadow, says. You realize after a short bit of sleuthing that this man is the boss. He begins to talk with you but because of that Frito-catcher glued around his mouth, you haven't the slightest idea as to what he's saying. But you're a pro by now. Of course, you still have that Carol Channing smile (you've even thought of patenting it).

You nod politely and say, “uh-uh,” “oh,” “yes, of course,” and all those little phrases that couldn’t possibly get you into trouble... right? Your partner begins to appear quite visibly agitated and soon he/she is dragging you to the car and muttering something about you sleeping on the couch. It’s two days later when you realize that the boss had a bit too much to drink and you’d agreed to escort him to the quaint cottage he owns in Tahiti. Oops! Obviously your lipreading skills need some refining.

Or how about the block party your neighbors decide to throw? You bake your famous blueberry pie, put on something festive and march out to the tables to mingle with those who share your street. As you gather up the courage and enthusiasm to introduce yourself to those you’ve not yet met, someone mentions that you are hard of hearing, hearing impaired or deaf... take your pick. Everyone freezes. Smiles abound. Everyone starts to nod and just as you go to offer the person standing next to you a slice of your pie, you realize that the only one in your vicinity is the black lab that’s been peeing on your tulips for the past six months. You make a new friend.

Of course, if you’re like many with a hearing loss, your attempts to eliminate your isolation sometimes seem daunting. Sometimes, you just want to throw your hands up and say the heck with it... nobody understands. Of course, you know that’s not true. If it was, the “Say What Club” would not be the safe haven it’s come to be for so many of us. Sure, we all have our moments, some more than others, where we feel all alone in this huge “hearing world” (as they like to call it). But there are 28 million people out there who can relate in some small and in some big ways. If only one or two of them lived next door...

Isolation. The word alone is enough to make me don mime makeup and black clothes, march out to the park and annoy anyone and everyone who approaches me. I must confess that I’ve done that—you have no idea how many people would give their right arm to punch out a mime. So... it didn’t quite prove to be the outlet I was searching for. But hey, you can give it a try. If it doesn’t work for you either, remember that even though you are “set apart” from some, you’re also closer to others than you were before. Consider how many of the people in the “Say What Club” [and others like it] would you have the honor of knowing and loving if you didn’t have a hearing loss?

We may be isolated in the big scheme of things but we’re also privileged to know that there are people experiencing the same things. If nothing else, it can help you appreciate things in life that you never took the time to notice before—how beautiful and peaceful the sunset is—the smell of the wild flowers that are growing near your home—oh, and how friendly the black lab that’s peeing on them is.

Everyone will react and feel differently about their situation but I think that applies to just about every circumstance possible. So the next time you’re feeling set apart, isolated, neglected, ignored, discriminated against, name your feeling, perhaps the best thing to do is not to accompany your boss to Tahiti nor share a slice of pie with the lab with a weak bladder nor die of thirst because you can’t stand the rejection. Perhaps you should sign on to the Internet, check your emails, send a post to SWC, call those in a support group near you or just say to yourself, “Self, I want to spend time with you.” After all, who will ever know you better?



CapTel Customer Service Representatives are Easy to Reach, Ready to Assist You
By Renee Pasciak
(CapTel Customer Service Representative)

Are you tired of calling a company for customer service and receiving nothing but a recording telling you to hold for ten minutes, or an automated system that doesn't answer your question? If you're a CapTel user and need assistance with your captioned telephone, you can reach a customer service representative directly via phone, TTY, FAX, e-mail or mail. Customer Service representatives are readily available 8am-5pm (Central Time) Monday through Friday. CapTel Customer Service is unique in its dedication to customers and strong consumer support.

CONTACT CAPTEL CUSTOMER SERVICE:

1-888-269-7477 Voice/CapTel
1-800-482-2424 TTY
1-608-238-3008 FAX
1-866-670-9134 Spanish
captel@captelmail.com
www.captionedtelephone.com



CapTel Customer Service
Ultratec, Inc.
450 Science Drive
Madison, WI 53711

Whether you are experiencing a specific problem, such as being disconnected during your phone calls, or just have a question or need some information about your CapTel, feel free to contact Customer Service for assistance.

Additionally, CapTel Customer Service can provide helpful tips for making your captioned calls go smoothly. For example, if you're trying to call a business or someone unfamiliar with CapTel, you may find that they hang up on you while you're waiting for the captions or reading the captions. By utilizing the phone's signal meter (the little square in the upper right corner of the display screen), you can tell when someone is speaking (the box flashes) and when he or she has stopped (the box is no longer moving). You can also start speaking as soon as the captions have connected, which is indicated by the row of stars ***** that appears on your display.

Further tips and troubleshooting suggestions are available in the CapTel newsletter, which is published quarterly by CapTel. To sign up, please contact CapTel Customer Service. The newsletter is available by e-mail or standard mail. You can check out past issues that are consumer-support orientated at: <http://www.captionedtelephone.com/news.phtml>.

CapTel Customer Service can help you in many ways from set up, to troubleshooting, to maximizing use of all the phone's features. You also can register your preferred home long-distance carrier so any long-distance calls you make with CapTel are billed to your account's established billing package. Give them a call today!

THANK YOU

Many thanks to those of you who have renewed your membership in ALDA-GS for the year February 2007 to February 2008.

Paul Arabas
Darshan Arora
Jerry Barnhart
Dominick Bongiorno
Elinore Bullock
Rev. Cathy Deats
Doreen Dougherty
Kathy Dylewski
Debbie Erickson
Diana Fanuel
Amy Farese
Kendall Franklin
Judy Ginsberg
Carol Granaldi
Eileen Hollywood
Judy Jonas
Kathy Kady-Hopkins
Nancy Kingsley
MaryAnne Kowalczyk
Diane Limey
Susan and Ralph Marana
James and Mary Lou Mayfield
Molly Meyers
Richard O'Neill
Benay Quadrel
John Riley
Karen Rogers
Sheila Shuford
Holly Sparano
Barbara Windholz
Tony Yuppa

And thank you for the donations!

Kathy Kady-Hopkins
MaryAnne Kowalczyk

OPEN CAPTIONING SERIES AVAILABLE AT NEW JERSEY'S PROFESSIONAL THEATERS.

By Deb Cooperman

In an effort to create opportunities for the more than 700,000 people in New Jersey who have some degree of hearing loss to enjoy live theatre, the Division of the Deaf and Hard of Hearing (DDHH) in partnership with the New Jersey State Council on the Arts has granted the New Jersey Theatre Alliance \$45,000 to market and administer The Open Captioning Series – a group of performances at the state's professional theatres.

The Open Captioning Series is the first of its kind – a statewide program – that will provide 32 open captioned performances from Teaneck to Cape May, Red Bank to Hackettstown. Patrons will be able to create their own “mini-subscription” of Open Captioned performances through the Theatre Alliance's Sampler Series – a discount ticketing program that makes it possible for patrons to see performances at up to 4 of the states professional theatres for just \$70. The free Open Captioning Calendar details dates and times of the program and is available through the Theatre Alliance.

The calendars will be available in mid-May; you may email the Alliance at info@njtheatrealliance.org to request one, or you can download it on their website at that time as well.

Until then, mark your calendars with the following dates of scheduled Open Captioning Series performances in May and June:

May 13 at 7:30pm - Seven Brides for Seven Brothers at Paper Mill Playhouse in Millburn

June 3 at 2pm Painting Churches at Women's Theater Company in Lake Hiawatha

June 8th 7:30 & June 13th 8:00pm
Pirates! at Paper Mill Playhouse in Millburn

PREPARE FOR EMERGENCY
Are you ready? Are emergency preparedness systems ready?
by
Barbara Raimondo, J.D.

In recent times the world has experienced major disasters -- some natural, some man-made, some a little bit of both. By their nature, catastrophic events take us by surprise. After all, if we knew they were coming we could try to prevent them or lessen their impact. Now federal, state, and local governments are making plans so that if and when an emergency does strike they will be prepared.

A 2004 report issued by the Deaf and Hard of Hearing Consumer Advocacy Network (of which ASDC* is a member) and the Northern Virginia Resource Center for Deaf and Hard of Hearing Persons, "Emergency preparedness and Emergency Communication Access: Lessons Learned Since 9/11 and Recommendations," highlighted the short-comings in emergency management systems in regard to how deaf and hard of hearing persons are served. That report was the impetus for movement within the deaf and hard of hearing community to improve these systems.

Subsequent to the release of the report, a Congressional briefing sponsored by the Congressional Hearing Health Caucus (CHHC) was held. CHHC is a bipartisan, no-dues caucus of members from the House and Senate committed to supporting the needs of those who are deaf or hard of hearing. Founded in 2001, CHHC highlights the issues of critical importance to those with hearing loss through periodic briefings and correspondence with all Members of Congress. The CHHC co-chairs are Rep. Jim Ryun (R-KS), Rep. Carolyn McCarthy (D-NY), Rep. Jim Walsh (R-NY), Rep. Lois Capps (D-CA), Sen. Norm Coleman (R-MN), and Sen. Tom Harkin (D-IA). ASDC is active in Friends of Hearing Health, an organization that provides information to CHHC.

Held while southern states were still recovering from the effects of Katrina and Rita, the briefing covered the demographics of people with disabilities in the region and actions agencies took to try to meet their needs, the situation of deaf and hard of hearing people during emergencies generally, and the specific experiences of deaf and hard of hearing persons during the hurricane emergencies.

Dan Sutherland, Officer, Office of Civil Rights and Civil Liberties, U. S. Department of Homeland Security, was the first speaker. Mr. Sutherland outlined the impact of Hurricanes Katrina and Rita on individuals with disabilities and highlighted the efforts of government agencies to try to meet their needs.

He described the efforts of the Federal government under Executive Order, 13347, Individuals with Disabilities in Emergency Preparedness. This order requires federal agencies to coordinate their efforts in emergency preparation. The work of officials under this executive order has resulted in several actions pertaining to the deaf and hard of hearing community. One is the sanctioning of television stations under Federal Communications Commission rules for new captioning information. Another is the granting of funds on a consortium of organizations led by Telecommunications for the Deaf, Inc. to develop model emergency preparedness community education programs for their consumers throughout the U.S. A third is to ensure the telephone relay systems receive priority restoration of telecommunications services after a disaster.

Emergency Preparedness cont.

Other actions taken by federal agencies focus on and include deaf and hard of hearing people in the broader disability community.

Cheryl Hepner, Vice Chair of the Deaf and Hard of Hearing Consumer Action Network (of which ASDC is a member), and Executive Director of the Northern Virginia Resource Center for Deaf and Hard of Hearing Persons, was the next speaker. She emphasized that a top priority in an emergency is communication: to learn that there is an emergency, to learn how to protect ourselves, and to learn how to access resources during recovery. She talked about how critical it is to build a national network for preparedness, response and recovery. A national network must provide a knowledge bank to offer technical assistance, research, education, training, planning, advice and consultation, and development of model programs and services. She said that deaf and hard of hearing individuals must be actively involved in a number of areas such as equipment testing, disaster exercises, and training of public safety and security personnel.

Dixie Ziegler, Vice President of Hamilton Relay, who sponsored the event, gave an account of how her company offered assistance to evacuees and to organizations attending to the needs of evacuees, such as the Red Cross, and to the shelters set up throughout the state. She remarked that many responders simply did not know how to serve deaf and hard of hearing people. For example, when Hamilton colleagues visited shelters and asked those in charge if any deaf or hard of hearing people were there, they were told no. However, it was later determined that there were deaf and hard of hearing people in these shelters.

Responders were eager to learn how they could better serve deaf and hard of hearing individuals so Hamilton provided some basic training on the spot at several shelters. In addition, materials were left to assist in communication, as well as information on how to contact Hamilton for equipment and other communication assistance.

We have seen how vulnerable we can be when we --- or our government agencies -- are not prepared for emergencies. As individuals, we must do what we can to protect ourselves in our homes. And we must educate the government at all levels to ensure that their emergency preparedness plans cover the entire population, including deaf and hard of hearing persons.

**For more information, please go to:

<http://www.cepintdi.org/>
www.dhs.gov/disabilitypreparedness
<http://www.nvrc.org/>

*American Society for Deaf Children

(Reprinted from The Endeavor, Volume 4, 2005)

With thanks to Jenny Beilis for sharing this with us.

HYBRID HEARING

Reprinted with permission

About 28-million Americans are hard of hearing. Many of them have trouble hearing higher frequencies. Hearing aids don't always help and devices like cochlear implants are only reserved for the worst cases -- until now!

Hybrid Hearing

"When I was about 40, I started noticing a plugged up feeling, like I had a cold," says Kathy Barger.

But she didn't have a cold. She actually had a hereditary disease that was causing her to go deaf.

"I couldn't quite hear as distinctly as before," she says.

A hearing aid didn't work, and more bad news was on the way.

"I got the news that I did not qualify for a cochlear implant," says Kathy.

Cochlear implants are typically used as a last resort because they destroy any residual hearing patients might still have. Kathy had too much hearing left to be eligible. Then she learned of a new, hybrid version of the implant.

Unlike the traditional model, the hybrid cochlear implant only adds high frequencies, so patients can hear distinct sounds -- like consonants. The words "sat" and "fat" can both sound like "aaahhh.", but the hybrid implant allows patients to tell the difference between the "ss" and "fs."

"It's like whoa, I heard that! It's sort of shocking because you're used to not hearing that, and all of a sudden, it's 'Gee, I can understand that,'" says Kathy.

Doctors implant the device in the inner ear to stimulate auditory nerves.

"I consider my job, putting in the implant, the easiest part of the whole procedure. The real work, the heavy lifting, comes after the fact," says Dr. Lawrence Lustig, an Ear Surgeon at the University of California, San Francisco.

"Let me know when you hear the beeps," Kathy is told during testing.

Kathy must work for months to re-learn how to hear, but she says it's well worth the hard work!

The hybrid cochlear implant is currently being tested in clinical trials. If it gets FDA approval, an estimated 50-thousand people could benefit from it. That's twice the number of people who have a traditional cochlear implant.

Doctors say the device may be especially helpful for older people who lose their hearing -- they, too, have trouble with high frequencies.

If you would like more information, please contact:

UCSF Douglas Grant Cochlear Implant Center San Francisco, CA 94143



ALDA-GS FAMILY NEWS



Judy Ginsberg announces:

“At last I am a Grandmother! Sharon and Andras are the proud parents of a little girl

Renata Anne Videki

Born, April 3, 2007, at 8:23am weighting 6 pounds 12 ounces and is 19 inches long.”

Congratulations, Grandma Ginsberg

Nancy Kingsley was recently recognized by the Division of the Deaf and Hard of Hearing for her years of service to those with hearing loss in New Jersey. Her award reads:

The New Jersey Division of the Deaf and Hard of Hearing
and its Advisory Council Honor
NANCY KINGSLEY
for her dedication, time, and energy
while advocating for people with hearing loss
in the State of New Jersey
in various positions as an advisory council member
and other roles in community organizations
January 2007



In her response to this award, Nancy said, among other things, that she had hoped to relax a bit from advocacy now that she has moved to Pennsylvania, but has already become involved with making things better for people with hearing loss over there simply by trying to shop through the relay system and go to the movies. Her efforts with a department store rewarded her with a \$100 gift certificate! She concluded that she has always been interested in helping those with hearing loss...*(and it seems she always will be)*. Nancy added that she loves living near her family, but misses her New Jersey friends.

Ed: Imagine having worked so hard in New Jersey, Nancy has to fight old battles all over again in PA!!



Happy Birthday ALDA-GS

