GRACE W. TIESSEN RECEIVES THE KEYSTONE AWARD

By Terry Portis, Ed.D., Executive Director

Atlanta, June 2003. Congratulations! You have been chosen to receive the SHHH Keystone Award.

Persons honored are part of a select group whose outstanding achievements and contributions are significant in the establishment, advancement and continued success of SHHH as a national organization. Their names are inscribed on a plaque at SHHH headquarters. California winners of the Keystone Award are:


Grace, you are one of those unique and highly motivated people who come forward to make real the ideals of SHHH. When asked for your thoughts about your involvement in SHHH, you said, “I wish to thank Rocky Stone from the bottom of my heart for founding SHHH. SHHH has given purpose to my life—advocating for hard of hearing people.”

With a lifelong severe hearing loss, you earned three bachelor’s degrees and retired from the Jet Propulsion Laboratory in Pasadena, California, as a Software Engineer. It was not surprising that you would serve in key leadership roles as President of the SHHH-CA Board of Trustees, 2001-03, and the San Gabriel Valley Chapter, 1985-90. You have served as Editor of the award-winning state newsletter, The SHHH Californian, since 2000 and as Webmaster for the award-winning www.shhhca.org since 2002.

Grace reached out beyond SHHH to impact services throughout California for adults and children with hearing loss.

• Deaf Education Coalition (DEC), largely a group of Deaf organizations, was instrumental in passing AB 1836, Deaf Children’s Bill of Rights, in 1994. In 1995 DEC held an Education Summit at which Grace testified, giving statistics showing that most students with hearing loss were hard of hearing not deaf, and that hard of hearing people needed to be represented on any advisory committees.

• She then joined DEC in 1996 to represent SHHH and was named to the California Department of Education, Advisory Task Force for the Deaf and Hard of Hearing (1996-98)


• She represented SHHH on the Deaf Education Coalition (DEC) which initiated and passed the Newborn Hearing Screening bill, SB 555, and was asked to join the Department of Health Services, Newborn Hearing Screening Advisory Group, 1999-.

• She is a member, Hoh/D subcommittee, of the Low Incidence Disability Advisory Committee (LIDAC), which advises the California Department of Education, 1997-

• Currently she and other SHHH members are working with Kaiser Permanente HMO at the national level to make all programs/facilities communications accessible 2003-

A colleague said of you, “Grace donates energy, time, and money to help others help themselves. She actively crusades to get information out about hearing loss and to find help for those coping with it.” Grace you are not average in anything that you do, you are spectacular. You give your heart and soul to improving the quality of life for all people who are hard of hearing.

Your name has been inscribed “with our love and thanks” on the Keystone Award Plaque on display in the SHHH national office. Congratulations!

BEST OVERALL STATE WEBSITE

Our new website, www.shhhca.org, received the Best Overall State Website Award at the Atlanta Convention in June. Designer: Cheri Lee; Webmasters: Grace W. Tiessen and mbdbdesign.

Every California chapter is now linked to our website. The chapter websites will be updated every two months in order to keep the Chapter information up to date.

Watch your website for the latest news. A fact sheet sent out by Brenda Battat has just been added. Look at photos from the Atlanta Convention.
LATEST STATISTICS ON COCHLEAR IMPLANTS

Facts on Cochlear Implants
- Approximately 70,000 people worldwide have cochlear implants.24
- Approximately 25,000 people in the United States have cochlear implants.25
- Nearly half of all cochlear implant recipients are children.26
- Cochlear implants can help an estimated 200,000 children in the United States who do not benefit from hearing aids.27
- The demand for cochlear implants is increasing annually by 20%.28
- Approximately 250 hospitals across the country perform cochlear implant procedures.29
- A recent study on cochlear implants demonstrated that special education in elementary school is less necessary when children have had "greater than two years of implant experience" before starting school. These children are mainstreamed at twice the rate or more of age-matched children with profound hearing loss who do not have implants.30
- The benefits of a cochlear implant to society amount to a lifetime savings of $53,198 per child.31
- By the time a child with hearing loss graduates from high school, as much as $420,000 can be saved in special education costs if the child is identified and given appropriate early intervention.32

References:
- 26 National Institute on Deafness and Other Communication Disorders, www.nidcd.nih.gov
- 29 Cochlear Corporation, www.cochlear.com
- 32 National Center for Hearing Assessment and Management, www.infanthearing.org

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HEALTHCARE ACCESSIBILITY
KAISER PERMANENTE WILL MAKE
NATIONAL EFFORT
THANK YOU, GAYLE TANG

By Grace W. Tiessen

Working with Kaiser Permanente (KP) has moved to a whole new level. KP and SHHH will partner at the national level to develop a nationwide training program, using Distance Learning technology, and a revised Listening Closely to the Hard of Hearing Population training manual.

Gayle Tang and Shari Samuels were speakers at the Plenary Session during the SHHH National convention in Atlanta. Gayle is Director, National Linguistic & Cultural Programs, National Diversity Department and Shari is Program Manager, ADA Compliance.

In California, KP is a not-for-profit HMO serving six million members or one-fifth of the population of the state. Nationwide there are 8.1 million members in 9 states and the District of Columbia.

Their talk focused on communication access to health care and KP’s efforts to include people with hearing loss. As an integrated health delivery system, KP is committed to providing “culturally competent care” to an increasingly diverse membership.

In order to confirm the participation of SHHH with KP at the national level, a meeting was held at the National convention in Atlanta. Gayle Tang shared her plans with the attendees from SHHH and invited feedback and suggestions.

Those in attendance were:
From SHHH National: Brenda Battat, Director of Public Policy and State Development, Teresa Burke, Board of Trustees member and Marcia Finisdore, Past President of the Board of Trustees.

SHHH at large representatives: Grace Tiessen, Past President of the SHHH-CA Board of Trustees, Margaret Arizona, Past President East Bay, CA SHHH chapter, Mary Clark, President, Orange County CA SHHH chapter and Sam Trychin and Janet Trychin, long time SHHH members, trainers, psychologist, and advocates for hard of hearing people.

SHHH thanks Gayle Tang and KP for listening to us.

STATE REPORT CARD ON NEW-BORN HEARING SCREENING
CALIFORNIA IS UNSATISFACTORY

The National Campaign for Hearing Health (NCHH), in partnership with the American Academy of Pediatrics (AAP) and the National Center for Hearing Assessment and Management (NCHAM), has just released new data indicating a significant increase in newborn hearing screenings since NCHH’s last annual report card in May 2002.

In November 1999, NCHH released data that indicated only 25 percent of U.S. newborns were screened for hearing loss. This year, 2003, the percentage of babies screened for hearing loss at birth has risen nationally, to 86.5 percent.

Here is the NCHH fourth annual State-by-State Report Card that analyzes the current status of infant screening.

The findings indicate the following:

- 40 Excellent States—Almost all babies are screened (90%+), and a statewide system for coordination, training, quality assurance, and follow up has been established.
- 5 Good States—At least 80% of babies are screened, and a statewide system for coordination, training, quality assurance, and follow up has been established.
- 6 Unsatisfactory States—Less than 79% of babies are being screened.

The unsatisfactory states are Alaska, California, New Hampshire, North Dakota, Ohio, Washington. In May 2002, California screened 34.5% of newborns; in May 2003, 57.7% were screened.

Each year more than 12,000 infants in the United States—one in 300—are born with a hearing impairment. Of these 4000 are profoundly deaf. In fact, hearing loss is the number one birth defect in the United States.

Although hearing health and pediatric experts have emphasized how critically important it is to have universal newborn hearing screening, currently only 38 U.S. states and the District of Columbia have laws mandating hearing screenings at birth. Without proper screening before the age of three months and appropriate intervention, it can have a severe impact on the development of communication skills, academic achievement, and social functioning of the child.

Early detection is vital to diagnosis and intervention.

To learn more, see www.hearinghealth.net.
What a busy and exciting summer this has been so far! I’m still reflecting on the wonderful week spent in Atlanta at the 18th Annual SHHH Convention. It was nice to see so many Californians there, as well as friends from all over the country whom we only see once a year at the conventions.

It was a pleasure to meet Steve Noroian and his lovely wife, Louise, in Atlanta. Steve is a member of the Diablo Valley Chapter, and our new district representative on the SHHH National Board of Trustees. I’ve heard so many nice things about Steve. I know he will be a true asset to the Board of Trustees.

Also making us proud was Grace Ties sen, Editor of this newsletter and Past President of SHHH-California. Terry Portis presented Grace with the Keystone Award at the Award Ceremony. This is a very prestigious award, and we congratulate Grace! In addition, our SHHH-CA web site also won an award. Grace is our web person, so you can tell from all these awards she has worked very hard over the last year.

This year was the first time I had ever attended the all day State Leader’s Workshop as well as the State Association President’s meeting. These meetings are held each year at the annual convention. Listening to our leaders from SHHH headquarters speak, as well as the exchange of ideas and information from leaders all over the country, was a truly inspiring experience. We have such a wealth of talented people from all over the country; it was truly an honor to meet them.

In addition to meetings and things of that nature, the convention was a lot of fun. Cindy Jagger was my roommate at the convention, and when we get together, we always have fun! One of the best get-acquainted parties I’ve ever attended was the Red, White and Blue Party. Of a patriotic theme, it was not only beautiful, but everyone was so enthusiastic, and it was lots of fun! Jim Montgomery was wearing some very unique glasses. Don and Flo Senger, Cindy Jagger, I and many others were all waving flags and having a great time. (See pictures of the Atlanta Convention at www.shhhca.org and www.hearingloss.org). I also managed to fit in a tour to Chattanooga, visit a couple places of interest on Sunday evening, and spend some time with my cousin, whom I hadn’t seen for almost 25 years.

Back here in California, it is “business as usual”. We are still looking for a chapter to host the 2005 SHHH-California conference. In order to have time to plan this event, we need to find a host chapter NOW. I’ve had one suggestion for a hotel in Santa Monica as a location, but we have no chapter in Santa Monica. So, if any of you are interested in working on the next conference, please contact me! I hate to see us not have a conference in 2005, but if we have no volunteers, that may happen. It is urgent we find a location and host chapter right away.

There will be a meeting of the SHHH-CA Board of Trustees on Saturday, August 23, 2003 from 9:00 a.m. to 4:30 p.m. The location of the board meeting is the HEAR Center, 301 East Del Mar Blvd., Pasadena, CA 91101. Directions are on the web site, www.shhhca.org. This is an open meeting, and any SHHH member is welcome to attend. Space is limited, so please let me know if you wish to attend, so we can be sure to have enough seating (sstreeter@shhhca.org).

Hope all of you are having a happy and safe summer.

Best Wishes, Sandi

Sandi Streeter

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Cochlear Americas, manufacturer of the Nucleus cochlear implant, awarded Self Help for Hard of Hearing People (SHHH) a $15,000 challenge grant contingent upon SHHH’s raising an additional $25,000 by July 1, 2003, in order to open a National Information and Training Center for Hearing Assistive Technology (NITC-HAT or The Center).

SHHH has matched the grant, so The HAT Center can now officially start. Dana Mulvany will be the HAT Coordinator and Dr. Portis is putting together a National Advisory Board, chaired by Mark Ross, which will include industry representatives and experts in the field to provide support and guidance for Center activities.

The Center, to be housed at the SHHH offices in Bethesda, MD, will serve as a key resource on all aspects of technology for people with hearing loss and their families, professionals and educators in the field, industry and government personnel, media representatives, and others.

“Cochlear implant technology is far more advanced today than ever before; however, assistive technology continues to play an important role in maximizing outcomes in a variety of settings especially difficult listening environments,” said Donna Sorkin, Vice President, Consumer Affairs, Cochlear Americas. “While Cochlear makes every effort to ensure that its technology is easy to use with other systems, it recognizes the importance of such a center and is pleased to be the first to partner with SHHH on this significant development. We hope that in stepping up to commit now, other companies will join us in supporting SHHH.”

The HAT Center will serve as a Washington, DC, area resource providing hands-on opportunities for learning about assistive technology and the way it stretches the benefits of hearing aids and cochlear implants. More importantly, the impact of the HAT Center will be expanded nationwide as the HAT Center staff promotes better understanding about hearing assistive technology, teaches others how to organize state-of-the-art demonstration centers in their communities and provides ongoing support to a variety of governmental, nonprofit, and other institutions.

Technology and resources will include devices compatible with cochlear implants and hearing aids; assistive listening systems and devices; adaptive telecommunication products and services; alerting devices; captioning tools and more.

The HAT Center is being established in response to the growing demand for practical information about how people with hearing loss can independently improve their access to communication. SHHH Executive Director, Dr. Terry Portis, says “Technology is vital for enhancing communication for people who are hard of hearing. The HAT Center will focus on providing relevant and leading edge information as well as promote the importance of hearing assistive technology. We believe this effort will make a critical difference in improving the quality of life of thousands of people across the country.”
Part 1 of two parts

COPING STYLES OF PEOPLE WITH HEARING LOSS

How do people cope with hearing loss? Are there similarities? Are some styles more adaptive, thus helping the individuals live more satisfying lives? Studies have shown that many different styles exist but a few generalities can be made. See if you can find yourself in this group. (The use of masculine pronouns represents individuals of both sexes.)

DENIER – This person does not acknowledge his hearing loss. If he doesn’t acknowledge it, he doesn’t have to accept the responsibility of it and doesn’t have to deal with it.

PASSIVE – This person realizes he has a hearing loss and that there are probably things he can do about it, but either chooses not to do anything at all or may just not get around to doing anything to improve the situation.

DEPENDENT – When this person doesn’t hear something, he depends on either a spouse or other member of the family to speak up for him. He avoids making any moves towards being assertive or discovering how to get along on his own.

CRITICIZER – This person is great at blaming others for his inability to hear. Common things this person will say are, “You’re mumbling!” or “I can’t hear you because you don’t speak up.” Obviously, he believes the fault for misunderstandings lies with the speaker rather than with him.

RESIGNED – This person has accepted the fact that he has a hearing loss and looks back on his days without a loss as the “good life”. He has resigned himself to his loss and believes life will never be as good again.

STRATEGIZER – Thinking ahead of time about how he can get the most out of a communication situation is the key to this person’s strategy. He strives to do all he can to keep communication lines open with friends and family. Because he plans ahead, he can avoid common pitfalls that often break down relationships and can face with confidence even difficult situations.

ACTIVIST – It is not enough for this person to do all he can to improve his own communication abilities, so this person also acts on the need to improve the communication of others who have hearing losses. His own experiences help him to help others.

IN TRANSITION – Some people are not solely in one style but are transitioning between two. Most common are those who are passive but are learning how to strategize so they can have more satisfying and productive relationships. It takes more work and acceptance of responsibility but is much more rewarding in the long run.

Carol Waechter teaches lip reading classes for Long Beach Community College. She is a member of and Professional Advisor for the Long Beach/Lakewood SHHH

IN MEMORIAM DR. HOWARD P. HOUSE, 1908 – 2003

Howard Payne House, M.D., founder of the House Ear Institute and pioneering ear specialist died August 1, 2003. He was 95 years of age. Dr. House dedicated his 64-year career to the advancement of auditory research. Perhaps his greatest contribution was the establishment of the House Ear Institute. Begun as a one-man laboratory, the Institute is now housed in a five-story building with a staff of more than 175 people.

House's father, Milus M. House, D.D.S., a researcher and pioneer in orthodontics, played a pivotal role in his son's career by suggesting he travel and learn from the finest ENT specialists of the day. After graduating from USC Medical School in 1935, he traveled the world, observing the work of ear surgeons throughout Europe and the United States. In 1946 he founded the Institute with a plan to enhance hearing research by bringing together and developing the ideas of ear surgeons worldwide.

Dr. House perfected the wire loop technique, to replace the stapes bone of the middle ear and developed procedures to reconstruct middle ear parts. This stapedectomy procedure restored hearing to people with otosclerosis.

The Institute became the first medical organization to film surgical procedures by adapting movie cameras for use with a surgical microscope, thus creating professional medical training videos.

Dr. House was also instrumental in the development of the Cochlear Implant, a device which has restored hearing to more than 70,000 people worldwide.

Appointed Chair of the Occupational Safety and Health Administration Subcommittee on Noise in 1947, Dr. House directed a national study on industrial noise. This study set the OSHA hearing conservation standards that are still in use today.

Dr. House was a long-time medical advisor to and supporter of SHHH. We will miss him.
WRAPUP - ATLANTA CONVENTION, JUNE 2003

by Grace W. Tiessen

The 18th Annual International SHHH Convention was a big hit. Over 1,000 participants gathered at the Atlanta Hilton for fun, information, and connection. There were workshops galore, the best exhibitors presenting their finest in goods and services, and everyone I spoke to said it was one of the best conventions for hearing loss they had ever attended. There is no question in my mind that people who attend and participate in our conventions are wonderful, warm, and exciting people.

At the Opening Session, Terry Portis, SHHH Executive Director, told us that he had received his Ed.D in Counseling Psychology from Argosy University just three days earlier. Congratulations, Dr. Portis.

Dr. Portis said that SHHH is striving to provide leading edge information. Its website had 800,000 hits last month. It now has a network of 14 state organizations and 250 local chapters. The national office gives people who are hard of hearing a voice on the national level. Funds have been raised to create a National Information and Training Center for Hearing Assistance Technology (NITC-HAT).

He said that while other organizations have "hard of hearing" in their title, they do not have the same clarity of focus that SHHH does. Our primary message is that hearing loss is a challenge you can overcome, you do not have to hide hearing loss, and you do not have to face hearing loss alone.

Heather Whitestone McCallum, Miss America 1995, gave the keynote address at the Opening Session, Overcoming Challenges to Attain your Dreams. She was a wonderful speaker and a very gracious sweet person who signed photos for us at the Welcome Reception.

Heather’s husband, John, recently learned that at age 33, he is beginning to lose his hearing. He plans to run for Congress, and Heather said she will make sure he looks out for the needs of hard of hearing people when elected. Heather talked about the challenge of being Miss America, of traveling 20,000 miles each month and of trying to understand the voices of different people every day. Since getting her cochlear implant, she has noticed how much less tired she feels when she is constantly around people.

She received her CI in September 2002, and is now making her first steps into the hearing world. She decided to get a CI because she wanted to hear her children’s voices, make further strides in achieving her goals and experience the hearing world. With the CI, she plans to help raise awareness among the community of people with hearing loss about the opportunities available for improving speech and language.

In 2002, the Board initiated an election process to create equitable representation from all ten SHHH regions. Representation from the ten regions is being phased in over a three-year period by holding regional elections in three regions the first two years, and in four regions the third year. This year we voted on regional representatives from Regions VII, Region VIII and Region IX. (California, Nevada, Arizona, Hawaii).

At the business meeting the new Board of Trustees were introduced. Steve Noroian was elected to represent Region IX, so now California has a representative. We had the pleasure of meeting Steve Noroian and his wife, Louise Noroian, in Atlanta.

Other Board members were Tommie Wells of Texas who represents Region VII. Elected to first term at-large positions were Teresa Blankmeyer Burke of New Mexico and Frances Clarida of Pennsylvania. Deanna Baker was elected to a second term at-large position.

Betty Coombs, Past President of the Inland Empire Chapter, participated in a workshop given by Donna Sorkin, Cochlear Implants and Seniors: Never too old to benefit! She gave her perspective on the surgery and benefits as a recently implanted 80+ years young CI recipient.

Mary Clark, President of Orange County SHHH Chapter, gave a workshop with Teresa Burke, called Hearing Loss in the Workplace. Both Mary and Teresa are hard of hearing and presented challenges and solutions that have worked for them in the hearing working world. They emphasized that there is not one solution that works for everyone.

And a Big Fat Greek Party!! We enjoyed a night out with good friends, authentic Greek food and wine, live music by the Greek Islanders, and watched a number of SHHHers line dancing.

And for 4-5 days I could hear/understand everywhere. Then, back to the real world, sigh.

Just imagine a life without amplified telephones. Or a life without closed captioning. Or a life without assistive listening devices. Do you remember how embarrassed you were about discussing your hearing loss? Do you remember not knowing what to tell people about how to help you understand what they were saying?

Because of SHHH, hearing loss has become a major issue of national concern. We have the kind of access no one would have dreamed of thirty years ago. But there is still a lot of work to be done. We need to reach out to others who don’t know that there is a better way to live with hearing loss. We need to be sure that wireless technology is compatible with hearing aids and cochlear implants so we aren’t cut out of the communication loop. We need to increase the amount of captioning available. We need to protect vital programs like newborn screening from budget cuts. We need to protect disability rights from erosion. We need to work for hearing aid insurance. The list goes on and on.

An equally important concern is keeping the organization financially healthy and working on our behalf. We’re not a manufacturing plant that can sell a packaged product. We’re not a retail store with clothes to offer. We’re not a Wal-Mart, a K-Mart or a Home Depot. We’re simply a not-for-profit organization whose purpose is to make it possible for you, for me, and for thousands of other people with hearing loss to lead full and productive lives.

As you can see from our pyramid, our Stairway to the Stars, we need contributions totaling $235,000 to help finance our operations this year. If you’ve already made a donation to SHHH in 2003, thank you! You are one of our stars! If you haven’t made your contribution yet, become a star today.

Please make your contribution on-line at www.hearingloss.org or send a check to SHHH, 7910 Woodmont Ave, #1200, Bethesda, MD, 20814. All gifts are 100% tax deductible.
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Both the Chapters and Desks are current as of August, 2003.
For changes/additions  email: gracetiessen@earthlink.net
CONTACT THESE DESKS WITH YOUR HEARING LOSS QUESTIONS OR CONCERNS!

Desks are volunteers with expertise in subjects that interest hard of hearing people. They will answer your questions, give advice or just lend an ear, depending on your specific needs.

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To find an SHHH group near you or to start a new SHHH group
See page 9 for address/phone

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SHHH is the nation’s leading membership and advocacy organization for people with hearing loss. It is an international, non-sectarian, educational organization of people with hearing loss, their relatives and friends. It is devoted to the welfare and interests of those who cannot hear well, but are committed to participating in the hearing world.

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Shhhh-California publishes The SHHH Californian quarterly in mid February, May, August and November.

Our database consists of 3200 records: 1250SHHH members, 1330 California audiologists, 100 California Department of Rehabilitation Hard of Hearing/Deaf Counselors, 100 Itinerant Teachers of the Hard of Hearing or Deaf and others interested in hard of hearing issues.

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THEY CONNECT YOU TO THE WORLD.
SELF HELP FOR HARD OF HEARING PEOPLE, INC.

Supporting SHHH Chapters throughout California.

Who We Are
Self Help for Hard of Hearing People, Inc. is an international, non-sectarian, educational, consumer organization of hard of hearing people, their relatives and friends. It is devoted to the welfare and interests of those who cannot hear well but are committed to participating in the hearing world.

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SHHH-CA, California State Association of Self Help for Hard of Hearing People, is affiliated with the national organization headquartered in Bethesda, MD. Both are non-profit and tax-exempt. The SHHH-CA Tax ID number is 77-0033506 Anyone residing in California who has joined our national organization is a member of SHHH-CA.

Self Help for Hard of Hearing People, Inc. is the largest consumer organization of hard of hearing people in the United States.

Our Mission Statement:
To open the world of communication to people with hearing loss by providing information, education, support and advocacy.

Watch your websites for the latest news.
SHHH-National: www.hearingloss.org
SHHH-California: www.shhhca.org
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