

## **An Invisible Condition**

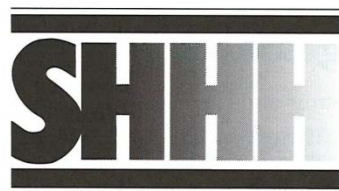
**AN  
INVISIBLE  
CONDITION**

*The Human Side  
of Hearing Loss*

**14 Years of Editorials  
from the *SHHH Journal*  
by  
Howard E. “Rocky” Stone**

*Foreword by Howard P. House, M.D.  
Chairman Emeritus and Founder, House Ear Institute*

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## Foreword

Today, the organization that Howard E. “Rocky” Stone founded in November of 1979, Self Help for Hard of Hearing People, Inc. (SHHH), is the preeminent consumer organization for people who do not hear well. SHHH — bearing that brave standard, “Make Hearing Loss an Issue of National Concern” is no longer a tiny grassroots organization of volunteers operating, literally, out of the basement the Stone home in Bethesda. Today, his concept of helping hard of hearing people to help themselves is widely accepted and emulated, not only throughout the United States but in many other countries as well.

Who is this man we all fondly call “Rocky?” And how did one man with the constant support of his wife and family, and a handful of volunteers, including hearing friends from his CIA days, accomplish this extraordinarily difficult task, this building of a consensus and a following of volunteers that today numbers in the thousands and has no other agenda but to help hard of hearing people?

I have asked myself these questions, not only now as I write the foreword to this book, but frequently over the years since I first came to know Rocky and SHHH. And the only way — indeed, the best way — to answer these questions is to delve into those editorials that Rocky began writing and which have been published in every issue of the *SHHH Journal* since its first appearance in print in the summer of 1980.

Those editorials, written under the intriguing ongoing heading, “An Invisible Condition,” give visibility to the man and to the organization. Those editorials, individually and in their entirety, have shaped this past decade of self help with their focus on the plight and the hopes and the aspirations — and the accomplishments — of hard of hearing people everywhere.

Beyond that, they are a look into a man’s soul. Poignant, funny, farseeing, backward glancing, forward looking, but always filled with a unique ability to portray the “humanness” of the person with hearing loss. I have never encountered so deep and so compassionate an understanding of what hearing loss means to the individual human being.

Rocky has educated me and countless others like me, whether within or outside the medical profession. He addresses the human condition first. He looks around and sees the worlds as it is, and he asks that part of the understanding that is given to other medical conditions be given to the person with a hearing loss. He uses these editorials to give us a look at our government, at the local, state, and national levels, and he addresses himself directly to all those who have a hearing loss, to their families, parents, siblings, friends, teachers, employers, and the entire healthcare team. Then, in deceptively simple language, he asks them and every element of our society to consider the impact of hearing loss on the individual person and the contribution every person can make, or can be kept from making, to our world, and to our country, and to our community, and to our own well-being and our own worth as human beings.

This book — this collection of all of Rocky’s “An Invisible Condition” columns — is the measure of a man. And the picture I get from it is of a superbly gifted, giving man, who saw World War II service at the age of 19, but never dreamed that the longest and most sustained fighting of his life would be on the battlefield of hearing loss.

While Rocky has written innumerable articles, has authored sections of books on hearing loss, lectured throughout the world and has received well-deserved honors too many to mention for his contributions to humanity, he will be remembered by countless thousands who already know and love him — and discovered by countless thousands of others who never knew him, until now — through the timeless beauty of this book. It is, just as certainly, a learning tool for all of us in the medical/hearing healthcare field. For me, personally, it is a book to learn from, to enjoy, to savor, and to pick up again and again as we struggle to help close the tremendous educational gap that still exists between the hearing and non-hearing fellow human beings among us.

Rocky took on a gargantuan task, and reduced it to its human proportions. His philosophy — and I quote his words from one of his earliest editorials — is simply:

“Increasingly, I have come to celebrate life. I may not be here tomorrow...Today, I must do the best I can — for myself and for others.”

Thank you, Rocky!

Howard P. House, M.D.  
Chairman Emeritus and Founder  
House Ear Institute

## Preface

John Locke once said, “The thoughts that come often unsought and, as it were, drop into the mind, are the most valuable of any we have, and therefore should be secured because they seldom return again.”

My column in the *SHHH Journal* was my means of taking Locke’s advice.

The column was my pulpit. It was the point from which I could share myself with you; where I could emphasize the basis of SHHH; where I could reveal to you why I was doing what I was doing. The pressure of time and work took away the planning content implied here. The column in implementation frequently depended upon what dropped into my mind an hour or so before my copy deadline. As you will see in this book some of the columns seem out of context from the whole. At times, the philosophic thread seems broken only to be picked up again later. Overall, in spite of several lapses, I think I achieved what I would have liked.

I love people. I am fascinated by their infinite variety; their contradictions; their heroism; their resiliency; their capacities to love and hate, to rationalize, to achieve beyond the odds, to somehow strive to do “the right thing.” I believe that any occurrence in life which makes us focus on the meaning of life, the few years we are here on earth, and what we are going to do with the time available, is healthy. I believe that hearing loss is such an occurrence. Yes, I am dreamer, but with a critically analytical mind. The future offers us many opportunities as well as dangers. If we can look ahead and decide what kind of future for SHHH is desirable, we can make the right decisions. Tomorrow is built on today.

SHHH is built on confidence in the human spirit and the determination to get hearing loss into a positive perspective. It’s working. In spite of the fact that many persons who had been in the field of hearing loss for years assured me that it would *not* work, it has worked. It’s working because the great majority of persons with hearing loss who became members of SHHH just needed a little help; a little company; a little assurance that they are okay; a little education, information, shared experience and support.

Change is a many-faceted word. Adjustment is a form of change and, given what they needed, SHHH members have changed their lives on a whole variety of levels. Some have gone from suicidal to function close to their optimum potential. Many have found happiness in their own ways. Most have survived a terrible threat to their well-being which had negative implications for them and those around them.

Because of my critical analytical approach, I could step aside and observe my dream come true. I could watch and evaluate the responses of people changing their lives themselves. It has been a sometimes frustrating, sometimes exhilarating and always fascinating experience.

My column reflected my thinking; in some cases, my beliefs; in other cases, something I had read which I felt was useful for you. I am one with you not only because I too have a hearing loss, but because I have confidence in you. Now, some generous persons have put all the columns together. I hope the overall message they bring to you is hope — without which life is meaningless. I know from letters many of you have sent me, that individual columns have served that purpose. Perhaps this collection can reinforce that feeling.

You, too, are in this book. Interactions are extremely important in experience. Your response to my efforts kept me going. Indeed your response moved me forward with confidence that we were on the same wavelength; that a real need was there and that SHHH was being soundly founded.

I am grateful to all of you who have influenced me over the past 13 years with your wondrous deeds and willingness to change to help yourselves and help others, too. You have sustained my confidence in the human spirit.

I am grateful, too, to those involved in bringing this book to fruition, particularly Brenda Battat, Marjorie Boone, Manell Brice, Barbara Harris (editor), Elaine Hill, Jeffrey Hughes, Myra Johnson, Joan Kleinrock, Michele Murray and Robin Titus.

Last and most important, I would like to dedicate this book to Alice Marie Stone. Without “Ahme,” as we call her, there would be no SHHH, and, of course, no book. She is the optimal positive person. A wife so supportive and loving, that all of us owe her a great deal.

Rocky Stone

# 1980

“Rocky speaks of hope, someone to love, and the dignity of work. He cites great minds, but also knows the fears, the hopes, of all of us. When he writes or speaks, he doesn’t teach or lecture, he *transforms*.”

**Pat Vincent, Grove City, Ohio**

*July/August 1980*

## **The Beginning**

The most pervasive physical handicap in America today is an invisible condition — hearing loss. Because it is invisible, it affects us in varying degrees of severity. The ability to deny it is enhanced. The smaller the loss, the more we or our parents are able to deny it, to conceal it, and to delay efforts to cope...to face the fact that adjustments must be made. The greater the loss, the more we or our parents are compelled to recognize it and to do something about it.

SHHH was founded for all of us — hearing and hard of hearing alike. It was founded because of my conviction that little progress toward prevention, detection, management, or possible remedies, can be made until we all better understand the reality of the situation.

Hearing loss is about communication. It is involved with the problem of listening and trying to understand what is being said rather than just hearing noise and isolated words. Amplification on the telephone permits me easily to hear the sound of another voice. My trouble is I can’t understand what the voice says.

Along the spectrum of hard of hearing people, there are many different problems, and the method of alleviation may vary. What works in one case may not work in another. But there is one common denominator. Hearing loss affects human beings. Being human is both unique and precious. As we expound our philosophy in these pages, you will see that belief as the foundation of thought and uppermost in our minds in what we advocate. Being human is both unique and precious.

In succeeding issues of this *Journal*, I will develop the philosophy of SHHH. It is your organization. We will attempt to make the invisible visible; to examine all aspects of this complicated problem to permit you to cope better; to show you how *you* can make a difference; to enter the consciousness of our society and develop a position in it equal to non-disabled people.

In the process, we will invite our members to share their experiences with us. Articles about individuals; about families; about our elderly and their special problems; about our children, all will attempt to capture the richness of spirit which characterizes hard of hearing people. Articles by professionals will appear, and while they may advocate one course of action or another, our philosophy is that each person must think through his or her particular situation and determine what is best in their specific circumstances.

We believe one should do whatever possible to communicate more effectively. We recommend that you use whatever methods are most suitable to your style, comfortable with your personality and compatible with your values. We will not argue whether sign language or speechreading or Cued Speech is better. We will examine all of them and let you decide. Because we believe we can arrive at “better communication through better understanding.”

In order for us to make SHHH truly representative of your wants, needs and aspirations, we must know what they actually are — not what we think they are. You must tell us. The more we hear from you, the better we will be able to serve you.

And now, let us begin...



*September/October 1980*

## **Counting: Hard of Hearing versus Deaf**

The disabilities that are most obvious to others, such as blindness or paralysis, aren't the most common. According to a 1977 study of the National Center for Health Statistics, the largest number of disabled people fall into these categories:

Deaf and Hard of Hearing.....	16,219,000
Blind and Visually Impaired.....	11,415,000
Lower Orthopedic Handicaps .....	7,147,000

About six percent of all impairments are in the top two categories. People over 65 account for 42 percent of all visual impairments and 40 percent of all hearing impairments. Some suffer from both.

Of the 16.2 million who are deaf and hard of hearing, fewer than 2 million are deaf. More than 14 million are hard of hearing. The National Center for Health Statistics estimates that over 8.5 million persons have impairment of a handicapping magnitude.

A study of the prevalence of hearing impairment in the Bay Area of San Francisco showed:

11.4 people classified as hard of hearing for every person classified as deaf (all categories);

55 people classified as hard of hearing for every person classified as prelingually or preprofessionally deaf. (Roughly, prior to age 19.)

These figures show that great need for work with and services to our large hard of hearing population. But communication services in state and federal vocational rehabilitation programs concentrate on the deaf. Many of our school children are hard of hearing, perhaps 25 times as many as are deaf, but their needs continue to be neglected. In fact, hard of hearing people are the largest and most neglected group in our handicapped population.

SHHH wants to change that. We can change the situation together if you share our desire. As we begin to better understand our problems and to cope with them, we will spread awareness of hearing loss and what it means to a large number of Americans.

Two years ago, in spite of 35 years of hearing loss, I knew practically nothing about the subject. I've learned. You can, too! And the reward is great! We will see manifestations of it in succeeding issues of this *Journal* as we try to make the invisible, visible.



*November/December 1980*

## **SHHH's First Birthday**

You are only one once. Birthdays are a time of joy, of sharing and, often, of review. I will spare you the litany of SHHH accomplishments during its first year. You are familiar with them. Suffice it to say we have done more than survive. We are a robust, healthy, young organization, full of zest for life and loaded with potential. I don't know what the survival rate is for organizations like ours. I do know we have come through our first year in style. And, in addition to hard work, it has been fun.

Reading mail from you is a growth process. Your experiences and the way you handle them are the stuff of greatness. There is a beginning here. A beginning which should lead into chapter formation all over the United States. That will be the bottom line for 1981! Not total numbers, although we have enrolled 500 members since June 1980, but total chapters. It is on the local level that help is most effective. Personal interaction, the pleasure of being with other people — particularly people who understand your situation — the re-establishment of confidence, shared projects, creative input, accomplishment, dignity restored — these are things that happen in chapters.

But chapters don't just happen. And that brings me back to the letters I receive. The writers of these letters are people who know — literally — that the need to confront their problem is a matter of survival. They cannot exist in a state of isolation. They are determined to survive. Interestingly enough, once you admit your hearing loss and work through your feelings in that new stage of reality, you may do far more than survive. You are able to initiate constructive actions to learn those communication skills appropriate to your situation.

Personally, I am excited about the potential for use of systems like audio loops, infrared, and amplified sound. Even though I am profoundly hearing impaired, I can derive help from each system under certain circumstances. We hope to educate you on what is available. We hope to whet your appetite for more, to stimulate your curiosity, and to exercise your imagination.

This is the season of hope. And we hope not for a magic cure to deafness, but for increased awareness of how we can cope better with our problems today and tomorrow. That increased capability is entwined with people — with each of us and each other. Self-absorption with our problems usually leads to withdrawal. We must once again become people who are family, group or community-oriented. And so, we must be willing to give and to risk. If our membership has those qualities, SHHH will be a unique and strong organization with a long, long future ahead of it. Only you can make it that.

Happy Birthday and Happy Holidays.

# 1981

“Our deepest appreciation to this man who so passionately believes in the human spirit — a belief and genuine love of people which kept him traveling from one end of the country to the other.”

**Sue Miller, Rochester, New York**

*January/February 1981*

## **SHHH at the White House Conference on Aging**

It was not a big gathering. It was just *very* important! They came from 25 states; 42 men and 46 women. Exactly half of them (44) had a hearing loss. Some of the 44 were deaf. Most were hard of hearing.

They were individual consumers, organizational representatives, people from various government agencies and academia, professionals, and some from private industry. They gathered in Washington, D.C. on January 11, 12, and 13, to examine the impact of hearing loss on older Americans and to make recommendations to the White House Conference on Aging (WHCoA), of which their Mini-Conference was a part.

Some of their work is reported on in this issue. More will be examined when the transcript of proceedings becomes available. But the important thing is the human impact. For most of the hearing impaired participants, the conference was “the most wonderful experience” of their lives.

Much was shared at the conference. Many of us who are hard of hearing have not been involved with others who are similarly affected. Being with one another for three days, interacting, exchanging experiences, sharing hopes, and realizing that we are not alone, gave us a wonderful feeling. And in that atmosphere of physical and psychological well-being, we accomplished much.

By the time you receive this *Journal*, a report with our recommendations will have been made to the White House Conference on Aging. That report will go to all 16 WHCoA technical committees, state conference coordinators, the 2,000 national conference delegates, and their 2,000 alternates.

The names of the 20 hearing impaired consumer delegates appear on page 12 of this issue. They should participate in various forums in each state so that our recommendations can be circulated widely *before* the National White House Conference on Aging.

You can help spread interest in the subject of hearing loss and those affected by it. A combination of the International Year of Disabled Persons (now in progress) and the White House Conference on Aging (November/December 1981) lends an added dimension to the ongoing problems of hearing impaired people of all ages.

It's time to have your say. Do it now. Together, we have a chance of being heard.



*March/April 1981*

## **“It Isn’t What You Do, But How You Do It”**

It had been a hectic five months starting in October: planning, organizing, convening the mini-conference for the White House Conference on Aging; writing the final report with too little data and too little time; getting the *Journals* out; answering an ever-increasing flow of mail; organizing a 150-person committee to plan and convene a local conference on all handicapped people to be held in April. Yes, it was time to stop for a moment — time to smell the roses.

My wife and I, with two old friends, decided to return to Zermatt, Switzerland, for a ski holiday in March. We stayed where we always stay, at the Hotel Rhodania, one of several small, comfortable places run by a Swiss family. One of the sons manages this particular hotel. He is in his mid-30’s (we first met him 10 years ago). We marveled at his effortless efficiency. Every evening he served a four-course meal to 48 people — alone. One senses a quiet pride in Christian’s manner. He does his job and he does it well.

Zermatt’s major industry is tourism. Those who do not wish to be “servants” soon leave. But as I watched Christian I saw, again, something that is very important to all of us in SHHH. It isn’t what you do but how you do it. Perhaps even more important is how you perceive yourself.

Sitting in the shadow of the Matterhorn on a crisp, clear evening is wonderful stimulus to philosophy. Knowing how we who are hearing impaired have had many experiences of humiliation; how many of us have developed self-doubt; and how many who become hearing impaired at an early age are unable to acquire the basic skills needed to compete effectively in our society; I wondered, where are we to find the courage, the confidence, and the trust needed to take action on our own behalf?

My experience leads me to conclude that we obtain these things by reaching out to each other. Hope flourishes in community, not isolation. That is why the concept of chapters at the local level is so important. Elsewhere in this *Journal* you will find suggestions to help you in organizing chapters. Transcending all of them, however, is the requirement for commitment to the most important values of our constituencies.

The concept of America as a “melting pot” is fading. We are becoming more aware that diversity is our strength. So, as we organize chapters we must understand and accept diverse interests, points of view, and life styles. But all these differences can be united around our belief in the basic principles of human dignity and the justice we all seek.



*May/June 1981*

## **Advocacy at the National Level**

SHHH is primarily an educational organization. Advocacy and representation are important elements of our function. What does advocacy, in our stage of development, at the national level require?

Five things:

- 1). Confidence in our philosophy.
- 2). Knowledge of what is important to the government.
- 3). A sense of history. Where are we going? Are the trends temporary or long-term?
- 4). A sense of timing. Knowing when to fight.
- 5). Creativity. Ability to devise programs suitable to the social/political climate of our time.

We believe that the national government must be sensitive and responsive to the needs of its people. The Reagan Administration clearly feels that the total needs demanding government assistance exceed the government's ability to respond and still carry out its other responsibilities to the whole community. This is the political reality with which we live.

Should the economic theories being followed today fail, would government resume a pre-Reagan posture? We don't think so. We think the historic trend is long-term. And, toward decentralization. It is true that disabled people have little political influence on the local level. We must develop more.

When we project the image of ourselves as persons wanting to be considered on the basis of our abilities rather than our disabilities, we are going to have to live up to the image. It is interesting to note that the National Federation of the Blind seems less perturbed by block grant funding than is the Association of Retarded Citizens. The reason could be that the blind are better organized at the local community level. Hard of hearing people must realize that whatever help we need beyond that which we can give ourselves and each other can best be marshaled in our own communities.

We are learning:

- how to build a constituency,
- where to enter our political system with impact,
- how to use it and influence it commensurate with our numbers.

But more time and increased effort from all of us is required before we will be effective. Which brings us to knowing when to fight.

We should support all handicapped people and their programs whenever they are within the context of our own philosophy. Some people do not vote on the basis of what they perceive to be broader interests of community and nation. In the latter case, advocacy is weakened.

But the real challenge to those of us who profess sensitivity and interest in bettering the human condition is to devise programs for the '80s and '90s that are more in keeping with the reality of our economic circumstances. And such programs must emphasize the

degree to which we are willing to help ourselves. Bobby Kennedy used to say that some see things as they are and ask, 'why?' He dreamed things that never were and asked, 'why not?'

Hard of hearing people are beginning to dream of many changes which will improve our lives. We should. But no one is going to do it for us. It is time to get our shoulders to the wheel.



*July/August 1981*

## **Enhance More People's Attempts to Help You**

Take a good long look at our cover scene. Multiply it by thousands. It may even seem familiar to you.

Individual and family strain. Stress. Bad feelings. Even an increase in violence. These are but a few of the results of the scene shown on our cover.

More than 50 percent of our older Americans suffer some degree of hearing loss. Perhaps 25 percent have significant bilateral loss. Most of them do not wear hearing aids; they cannot speechread well nor do they know sign language. Many have minimized their loss for so long that their ability to handle the problem is low. If they live in a multi-generational family, they have probably added greatly to the stress of each of its members.

Just about everyone watches television. The hearing impaired person wants to watch as much as everyone else, but the noise level involved in his or her effort to hear is often intolerable for hearing members of the family. We made suggestions on how to improve this situation in our January/February issue of *Shhh*. (See our "Special Report" on Alternative Listening Devices.) But those were suggestions of a technical nature. There are many other aspects of the problem which need examination.

One of them is empathy. Using the letters of the word, I once described empathy as an effort to "enhance more people's attempts to help you." A more precise definition is offered by two creative researchers from the University of Arkansas. Their article appears in this issue. While their conclusions are necessarily tentative, this type of research opens up new and important avenues to better relationships between hearing impaired older persons and their hearing friends and associates. Such training, if included in the preparation of all persons professionally involved with older people with hearing loss, could result in much more effective interaction between the two groups. The favorable implications for us (hearing impaired) are profound.

At the conclusion of the mini-conference for the White House Conference on Aging, we made the following recommendation in the training category: "Develop empathy programs for service providers, family, and federal policymakers to sensitize them to difficulties of the hearing impaired elderly." We believe empathy *can* be developed.

Since I have lived abroad much of my life, I am well aware that understanding a problem does not necessarily make you like it any better. But it should make you better able to handle that problem — and that's what we need to develop now. Failure to do so will only add to the multiple factors for the scene depicted on our cover.



*September/October 1981*

## **International Year of Disabled Persons**

As we enter the final quarter of the International Year of Disabled Persons (IYDP), we cannot help but ask, “What has been accomplished?” and “Where do we go from here?”

Alan Reich, president of IYDP, describes progress during the year as “outstanding.” While thanking everyone for their help, Mr. Reich assures them that “you are ensuring that this one-time IYDP opportunity truly will make a difference to Americans with disabilities — and to all Americans.” I wish I could agree.

Unfortunately, real progress requires action by the majority of people who now appear disinterested. Nor are current trends encouraging in this regard. Although many programs for handicapped people survived the Administration’s effort to include them in block grants to the states, that is only the first round in what almost certainly will be a much longer fight.

The IYDP did do many constructive things. But it remains for us, the handicapped, to deepen and expand commitments made during the year, to carry the struggle for acceptance as equals — and all that implies — forward, this year, next year, and the year after.

In regard to hearing handicapped people, a broad program of education to all Americans is needed to weave into one matrix the bits and pieces of accomplishment which occurred during the IYDP. Marjorie Skafta (see “Opinion”) urges a Hearing Awareness Program involving every discipline in the hearing health field. We agree.

In May 1982, PBS’s series, “The Hurt That Does Not Show,” is scheduled to air over some 310 stations. Using many of the themes developed for this series, perhaps the major components of the hearing health care field and consumer organizations could get together for a prolonged campaign of one or two years duration. In this way, whatever gains made during IYDP can be expanded.

One of the recommendations to the upcoming White House Conference on Aging reads: “Request the Secretary of Health and Human Services to develop plans for a national public education program for hearing health care. Involve appropriate public and private agencies, including consumer groups and public television.”

Should that recommendation receive positive consideration, we would be well on the road to doing what many of us feel is so necessary. Meanwhile, we should continue to organize ourselves and others to do the job without government help if that becomes necessary.



*November/December 1981*

## **SHHH's Seven Areas of Concern**

For those of you who came in late, it's our birthday. SHHH was incorporated at the end of November 1979. We are two years old!

We have had spectacular growth, broad involvement in issues affecting hard of hearing people, national publicity in print media, radio and television, and a growing awareness among our membership that SHHH is what we will make it. Chapters are springing up in areas where we did not even know the organizing was being done. More and more members are getting involved.

Through all these developments, the thing that impresses me most is the poignant (sometimes bordering on grim) need that is revealed in our mail. Generally, it is helpful to know someone cares. Specifically, it is better to actually *know* someone who cares. That is what happens in our chapters. There, the experience of relief in knowing we are not alone develops into the joy of participation in carrying that realization to others. That this could happen to so many in such a short time frame is gratifying indeed.

It is clear that the time for SHHH has come. Our membership growth is assured. Now we must develop our impact as a large membership organization by producing accurate information on issues that affect us most. In the first issue of this *Journal* (July/August 1980), we described seven study groups which we believe will give us the factual basis on which to make our weight of numbers felt. They are: Science and Technology; Architecture and Design (emphasis on communication access); Medical (emphasis on early detection, frank and honest diagnosis and special referrals); Attitudinal Research (with emphasis on combatting denial among us and fostering understanding among hearing people); Legislation and Regulation; Public Information; and Education (with emphasis on school-age children and continuing education for adults).

Each of these groups will consist of six or seven highly qualified persons in the particular field. They will meet three times a year in Washington, D.C., (or another suitable location) to review their specific area of concern, identify gaps, evaluate research suggestions, make recommendations, and perhaps pursue individual studies between meetings. The conference results will be made public. Recommendations will be processed through SHHH to the parties having authority and action capabilities.

As these groups develop, we will identify members and their specific areas of research. Funding for the groups is being sought from private and public sources.

Ideas on research, participants, and possible sources of funds are welcome. We hope, too, to hold open meetings of each group on at least one occasion every two years and to invite anyone interested in the particular area under examination. Help us to help you by giving us your reaction and requirements for the SHHH study groups.



# 1982

“I told Rocky I had a small hearing loss. He said, ‘There are no small hearing losses.’ He gave me more compassion in those few words than anyone else could in a 15-minute dissertation.”

**Teresa Gregory, Las Vegas, Nevada**

*January/February 1982*

## **Expanding Awareness of Hearing Loss**

On November 4, 1981, “Over Easy” featured Florence Henderson and the subject of hearing impairment. SHHH was the resource organization. Within a few days, we were inundated with mail. (High water mark was 601 letters in one day!) We received more than 2,200 letters in response to the program.

For me, mail call is always a learning experience. And so it was again. The majority of writers found the show rewarding. But too many missed something. Some thought, for example, that Florence Henderson had had a cochlear implant — and they wanted one. She didn’t. She was operated on for otosclerosis. Some thought that sensorineural deafness was now susceptible to surgical remedy. It isn’t. And so on — through many, many letters.

But whatever the misinterpretations, the thousands of people who wrote for more information are now more knowledgeable than they were. That is one of the reasons SHHH exists. To further clarify lingering misunderstanding, we are publishing an article by Dr. William House on cochlear implants. A careful reading of this article will reveal what it is and what it is not. The article clearly identifies those who can be helped and those who cannot.

The brothers House, Doctors Howard and William, run the House Ear Institute in Los Angeles. They both have a long and distinguished record as leaders in their respective fields. Howard House was Florence Henderson’s surgeon (and that of many, many other people). We have asked him for an article on those types of hearing loss susceptible to medical/surgical remedy. You will be reading more about the House Ear Institute in future issues.

Another frequent area of inquiry in the response to “Over Easy” concerned infrared. Many people wanted to know what theaters now have infrared. We asked Sound Associates (the New York distributor) for a complete listing and will publish it when received. Other correspondents wanted to know if infrared could be used on a personal basis outside theaters, churches, etc.

We contacted Dr. Barry Leshowitz at Arizona State University in Tempe, Arizona. Dr. Leshowitz has built an infrared light transmission hearing aid. He has received a grant from the Veterans Administration to continue development and miniaturization of his device. He calls it an Infrared Personal Hearing System. The results of our contacts are published in this issue.

Because hearing impairment *is* such a complicated subject, there will always be a number of misinterpretations of what is said on programs like “Over Easy.” The format, a combination of entertainment, discussion of serious issues and availability of a resource person or organization, opens the doors to millions who can seek further data if they wish. This is a service to be cherished.

Anyone involved in education knows it isn’t easy. The idea of getting people’s attention in order to convey desired information is certainly a good one. With a broadened audience, the subject then becomes worthy of in-depth discussion on a different type of show. And so it goes, when the demand is obvious, more organizations and media will be willing to service it. It is coming. The deaf have pushed vigorously into this area of mass education. Our growing presence, added to theirs, will eventually result in what we all want — greater awareness, better understanding, increased appreciation for hearing impairment and its consequences, and a more realistic interrelationship between hearing and hearing impaired people.



*March/April 1982*

## **Families — Support Structure or Battleground?**

Families. Support structure or battleground? Do they help or hurt? Most normal families probably do both. What can we do to improve our family environment; to help those closest to us better understand our needs and feelings; to add our constructive efforts to the enrichment of our basic community unit? We can begin by educating ourselves and then our family.

This issue of *Shhh* gives some insights into the problems of diagnosing hearing impairment that confront our family physician. Then we give you an example of how pervasive hearing loss can be in one family. (Twenty-nine members of Jim Hanson’s family were deaf!) JoAnne Gilmore shares with us some problems she found working toward an improved family relationship. Then Don Richardson describes how he reacted to having a hearing impaired person in one of his classes.

There are many other areas which need to be covered, so this is just a start. The fact is that we can be profoundly affected (for better or for worse) by other family members in relation to our hearing impairment. With the stakes so high, should we not make every effort to help them understand our problems so that their ultimate influence on us will be positive? And if we are parents of hearing impaired children, don’t we have a responsibility to learn as much about the problem as possible so that our relationships with our children develop in the reality of our circumstances rather than in an unattainable dream world?

Difference is not bad. But it *is* different, and it is necessary to explain why we act and react differently. Once that begins to sink in, all of us have a better chance to enjoy the fullness of our own potential.

My family knows, understands and accepts my difference in methods of communication. On my part, I don’t insist on getting every word. A frequent, unsolicited occurrence at our dinner table is my wife, son or daughter, to turn to me after a few

minutes of normal conversation and summarize what was said. I may need it; I may not, depending upon how closely I was attending; how tired I happen to be; etc. The point is, it is an act of love. It is an expression of their concern (and respect) for me. It is their way of keeping me in their lives. I like it! It makes me feel good — even when I had been able to follow the conversation.

With this type of deep interest in and concern for me, I attempt to reciprocate and accept many trade-offs. For example, a bevy of barking dogs drives me up the wall. But they are important to every other member of the family. The dogs stay.

Returning the love of family members is just as important as receiving it, for it is only in an atmosphere of mutual concern for each other that real progress can be made.



*May/June 1982*

## **Better Speech and Hearing Month**

May is becoming an increasingly significant month for hearing impaired people. The idea of setting up special time frames within which to concentrate on specific topics has taken root in America. May — the entire month — is that time frame for hearing and speech problems.

Over the past few years, national organizations concerned with those problems have formed a “Council for Better Hearing and Speech Month.” The Council has 23 members (SHHH joined the Council in March 1982.) SHHH organizers around the country have received a kit put together by the Council. It contains many helpful suggestions and outlines procedures for developing awareness of hearing and speech problems among the general public.

You — at the local level — have much to share with your communities. May is one of the best times in which to do so. National publicity is being generated by the Council, headed this year by Nanette Fabray. But this publicity must be augmented by activities in each community. Now is the time to share your concerns, illustrate your work and spread your knowledge in *your* community.

We can assume that each May will bring forth a flurry of publicity on hearing and speech problems. Using that as a peg on which to hang other activities or as a stimulus to new activity, we must develop year-round programs to sustain interest where it counts — in your community. If your chapter or group is not far enough in its development to fully utilize the month of May this year, start planning now for next year.

Awareness is intended to change attitudes. It is a never-ending job. We cannot simply make a big splash during May and then relax. We must integrate May into our overall planning, using it to highlight certain activities and to benefit from intensive national publicity on the subject.

We have learned a great deal in the last two years. That wealth of information should be shared with our hearing friends and the general public. May is a good time to begin.



*July/August 1982*

## **When Sound Becomes Noise**

We are immersed in sound. But when does sound become noise? And how does noise affect our physical and emotional well-being? Noise is unwanted sound. It is sound which has an adverse impact on us. It can make us angry, or just irritable; listless or unable to sleep. And it puts us at risk in terms of our hearing. Noise-induced hearing loss is the single greatest cause of hearing impairments today. And it is permanent! It won't go away. As yet, there is nothing we can do to make it go away. But we can do something to reduce the risk of noise. We can work toward prevention and toward the reduction of environmental noise.

Such activity involves choice. Many of us accept dangerous noise levels for convenience (for example, air conditioners, power tools, hair dryers, airplanes, etc.); some of us choose dangerous sound levels for pleasure (for example, rock or concert music at high volume via headphones); and others of us simply tolerate noise as a condition of employment. To exercise choice intelligently, we need accurate information.

The first thing we must understand is that hearing loss occurs at noise levels which many people believe are harmless. Certainly, the ear, as part of that marvelous human system we call "body," has built-in protection. Special muscles can tighten the eardrum against the surge of too much sound. Other muscles can pull the stapes out of the oval window so that it doesn't transmit damaging levels of vibration to the delicate structures of the inner ear. But any emergency system only safeguards a mechanism from the perils it was designed to protect against. The human ear cannot protect itself against high-pitched and long-lasting sounds. Nature won't save us. We must help ourselves.

In this issue, we explore some of the problems of noise in our environment — and what we can do about it. Make no mistake, the stakes are high. And we who sleep in continual noise will be awakened by silence.



*September/October 1982*

## **“I Miss the Sounds of Nature... But I Can Still Smell the Rose.”**

Louis L'Amour is a prolific writer of novels about the Old West. I've read just about all of them. I'm fascinated with the simple drama of survival based on the senses. A man alone in the woods would have difficulty staying alive with poor hearing. For example:

“Something was up there, something that moved with incredible softness. I was afraid...something was crawling about up there. It was a man. Rough cloth rubbed against rock.”

— from *Milo Talon*

“As we stood listening, there was a sound of men coming along the path...Deep within the forest, an owl hooted...it was no owl...although the difference was subtle.”  
— from *The Warrior's Path*

But, of course, those were days before we began systematically to destroy our hearing with noise.

My wife, Ahme, and I decided to get away from noise. We went to a “wilderness” camping area. (That means no facilities.) The illusions created by hearing loss went with me.

We were looking for a lake buried in a hilly and wooded area. When we finally found a pond, I assumed that was probably all we would find. We camped alongside it. Later, Ahme heard geese — almost certain verification by sound of another body of water nearby. Nevertheless, I exalted in the beauty of the spot and what appeared to me as complete isolation. Once I thought I heard the drone of a distant airplane, “It’s just beyond that tree,” Ahme informed me. Still, I believed there was not another person around for miles! (Ahme heard frequent sounds of automobiles. We were not exactly in desolation valley.)

The next morning I mentioned my surprise at having seen no birds. But Ahme had heard the calls of “whippoorwill, whippoorwill” during the night and she awakened to the songs of early morning singers. She mentioned the variety of night sounds of different insects into whose domain we had come, and she described a “conversation of frogs” whose sounds came from several different directions as if in good communication with one another.

As I watched ripples pass gently through tall treetops reflected clearly in the crystal pool, I marveled at nature. I learned, again, that we all live under the same sky but that we don’t all have the same horizon. It was a beautiful weekend.

Yes, I do miss the sounds of nature. But at least *my* survival is not dependent upon my hearing. And, I can still smell the rose.



*November/December 1982*

## **Hearing Loss and Mental Health**

Studies of deaf patients in hospitals have shown that diagnosis of schizophrenia was no more frequent than among hearing persons; and paranoid symptoms no more frequent among schizophrenics. With people who have become hard of hearing later in life, an excess of paranoia illness has been reported.

As we lose our hearing, things seem to change: for us, and for those around us. Our conceptions of each other, fed by interactions too often the result of ignorance or neglect, evolve. The emotional cost of this evolution is, as yet, undetermined, but some things are known. As our social and emotional contacts are hampered by problems of communication and perceived rejection, the process of socialization gradually shuts down. Empathy, control and social sense are, somehow, manifest differently. These things need to be better understood.

What are the major stressors of life? Where does hearing loss fit in? How does hearing loss affect the others? What does a combination of major stressors do to an individual in terms of adjustment, of coping? With life expectancy expanding rapidly and hearing loss an assumed result of aging (which we do not yet agree with), where is the needed research that might provide some insight for dealing with people who are in such double jeopardy?

Certainly, prevention and treatment of emotional disorders in young children who are hearing impaired is needed. But more! We need marriage and genetic counseling, increased community services, greater involvement of people who are hearing impaired in self help groups and broad dissemination of knowledge about hearing impairment, its causes, complications and possible remedies.

Professionals and para-professionals lose their hearing, too. They can use their knowledge to help in an area too sparsely populated with helpers. This issue of *Shhh* will examine some problems of hearing loss and mental health and include the experience of people in the field who, themselves, are hard of hearing.



# 1983

“His faith in me, as in every single person, gave me back faith in myself — so I could begin again to grow, learn, experience, and *share*. Thank you, Rocky, for your greatest gift: freedom...from fear.”

**Marjorie Boone, Arlington, Virginia**

*January/February 1983*

## **The Choice: To Start Again**

“Every day is a fresh beginning  
Every morn is the world made new.”  
— Susan Coolidge

Do you believe that? Even with a severe hearing loss diagnosed as nerve deafness about which little or nothing can be done? (Or so we are told.) I have profound nerve deafness and I believe it. I'll tell you why. Increasingly, I have come to celebrate life. I may not be here tomorrow. Then again, I may be here 30 years from now. Today, I must do the best I can; for myself, and for others.

One way of doing that is to make fewer assumptions and ask more questions; to continue to learn, to grow. Another way is to involve myself in areas of substance and with other people. Of course, my hearing loss impinges on all of these things. (It has for 38 years!) But I do them anyway. It is a matter of choice. I can let my hearing loss inhibit me, put me down, and eventually dominate me. Or I can do the best I can with it. I choose the latter. By doing so, I have enhanced my life immeasurably.

I will not contend that we are all masters of our fate. I do believe that most of us have a choice. In spite of the hassles of modern life, the threat of nuclear extinction, economic pressure, and all the handicaps particular to each of us, how we choose to lead our lives is the essential ingredient in determining the quality of life in our circumstances.

Nobody is perfect. Don't be too hard on yourself. Wherever you find yourself at any given time, you are okay. The big question then is, where are you going? That requires exercise of choice.

Information helps. When we think the deck is stacked against us, it is sometimes difficult to stay positive in our thinking. Nerve deafness is an example. This issue opens up a two-part discussion on that complicated subject. We hope to get it in perspective for you. Maybe you will find the future is not as grim as it is so often painted. You may even find that the present contains more avenues of help than you knew about. In fact, you *could* come to believe the words in the opening quotation. I hope so, because each of us deserves a chance to start again.



*March/April 1983*

## **Going to School with a Hearing Loss**

I have a vivid recollection of going to school with a severe hearing loss. It was 1945. I was 20 years old and recently discharged from the Army. I, and thousands of other veterans, enrolled at the University of Southern California. There were so many of us, that classes were inevitably large. Popular teachers often lectured in huge auditoriums. I always sat in the first row — always a little off-center of the microphone — so I had a reasonably good view of the speaker's lips. I stared (so much that I made a few teachers very uncomfortable). I concentrated. I never took notes. It never occurred to me that there might be an easier way.

After two years of increasing fatigue and wondering whether what I managed to understand was worth the effort, I requested a hearing aid from the Veterans Administration. I soon acquired a two-piece device looking something like today's walkie-talkies. One piece contained the microphone, the other was the battery pack. I carried them around in my briefcase stuffing them into my waistband at the beginning of class and removing them at the end.

It was not uncommon to see me rush into class as the lecture was about to begin, waving my arms and shouting, "Hold on until I am wired for sound!" My professors and peers were all very cooperative. The hearing aid helped reduce the strain of lipreading and my comprehension improved by using both. But it seemed to take forever to get used to the hearing aid. And the fatigue from lipreading — while somewhat less — never really went away.

When we accept, as we are beginning to, that education is a life-long process, going to school with a hearing loss has broader implications than one might think. When I returned to a university setting at age 54 with a profound hearing loss, I found much less cooperation — but that is another story.

This issue of *Shhh* focuses on the problems of a hard of hearing person in a mainstream school. Our emphasis, for the moment, is on children, but, there are many others like me whose association with this problem began as a young adult. May we share your experience please?



*May/June 1983*

## **Telephone Compatibility**

I have traveled a great deal since losing my hearing. In fact, I averaged one trip around the world for many years. It was while traveling that I experienced my greatest frustrations. Feelings of hopelessness, anger bordering on fury, great irritation, and sometimes just tired resignation. The problem was the telephone. Many times the phone was incompatible with my hearing aid. Frequently, particularly in hotels, the current was

far too low for me to use even with powerful amplification on my hearing aid. I was often alone — and totally dependent!

In the United States, at least, much has been accomplished in the area of compatible phones. It's not been easy. Coming up with a solution which serves those of us who need compatibility without too great an intrusion into other areas took hard work, patience, and a lot of skill. Of the many organizations involved, the Organization for Use of the Telephone (OUT) deserves special recognition. Year after year, OUT led the charge.

There are many honest differences of opinion on how best to serve what Senator Goldwater called "a narrow issue of universal service." Our system is based upon compromise, the willingness of divergent groups to come to some consensus. That consensus was finally reached in the *Telecommunications for the Disabled Act of 1982* (Public Law 97-410). A report on how the Act evolved is contained in this issue.

Now, if I visit a hotel with 500 rooms, I don't expect that every room must contain a phone I can use (although many hotels are so equipped). I do expect that if I tell the clerk I need a compatible phone in my room, one will be plugged in immediately. If I cannot achieve that, I'll holler. The chance of my cry being heard today is infinitely better than it was yesterday. That's progress.



*July/August 1983*

## **Building Bridges Toward Organizational Cooperation**

How do we go about building a bridge to the moon? People who are hearing impaired must keep one thing clearly in mind. We cannot allow our difference of methodology, emphasis, style or personality, to stand in the way of our basic commonality — hearing loss. We have to understand that honest difference of opinion is not an "attack" on another person or organization. We have to understand that while different organizations serve different needs and go about their business in different ways, there is a large area for agreement and cooperation among them.

Organizations of and for deaf people are getting their act together, while the actual organization of hard of hearing people has barely begun. The National Association of the Deaf is 103 years old. The Alexander Graham Bell Association for the Deaf is 93 years old. SHHH is 3 years old. We have learned from these older organizations and we can learn still more while working closely with them in the years ahead.

Hearing impaired people in the United States number 17.7 million. In terms of services, organizations of and for the deaf are focused on some two million people. Organizations of and for hard of hearing people are concerned with more than 15 million. In terms of awareness, research and legislation, all of our organizations should be interested in the entire United States population.

This issue of the *Journal* provides our readers with some basic facts about those organizations which focus on various aspects of deafness and hearing impaired people. Some are new, some are old. Some are large, some are small. Each has something to

offer. But progress toward building a bridge to the moon will be made in direct proportion to the ability of all these organizations to work effectively together. When that day comes, our impact on society will be commensurate with our quality and numbers. Then, in the words of an old song, "I'll be looking at the moon, but I'll be seeing you!"



*September/October 1983*

## **Assertiveness is *Not* Aggressiveness**

I had just finished speaking to an SHHH Chapter and was relaxing with a few members when it happened. My right elbow was suddenly encased in a vise-like grip from behind. The hand grasping my elbow began to tug urgently. Fortunately, I am neither pulled nor pushed very easily. I was able to keep from spilling my drink, finish my sentence and excuse myself to my companions, before turning to another experience in interpersonal relations. It was a man; pleasant looking but very anxious. He wanted to tell me that he did not think he needed training in assertiveness. (I had made several allusions to such training in my speech.) I wondered "why not?" He fixed me with a rather baleful glare and announced, "I'm aggressive enough. I can take care of myself!" Perhaps so, I thought, but at what price to others?

Assertiveness is *not* aggressiveness. Those of us with hearing loss often gravitate toward one of two extremes, withdrawal or aggressiveness. Neither is constructive. Assertiveness training is designed to help us take care of ourselves *without* intruding on the rights of others. Aggressive behavior (in the context of interpersonal communication) often leads to quarrels or fights. One assaults or invades. Assertive behavior is that which affirms in a positive manner, declares with assurance, avers. Admittedly, there is a fine line between the two. Assertiveness training helps us to understand the difference, broaden the distinction and emerge as constructive *and* confident participants in interpersonal communication.

Recently, I heard Dr. "Sal" DiMichael speak in New York City. Sal has been working with SHHH chapter members there and has generously given considerable time and energy to training them in assertiveness. I was so impressed by the man and his work, that I invited him to put on assertiveness workshops at our convention in 1984. He agreed.

His report, published in this issue of the *Journal*, should be of interest to all of us. The results were favorable and assertiveness training for hearing impaired people seems, to me, to have a great future. If your reaction is "Waddaya mean, I could use assertiveness training?"...then perhaps you are a prime candidate. Or, if you just don't think anything can help you...you'd be surprised!



*November/December 1983*

## **Climbing Mountains: Bringing Dream into Reality**

Why do we climb mountains? Most of us, at one time or another, have attempted to bring a dream into reality. Most of us have had the urge to go beyond the usual, to try something new, to be different. And some of us have accepted a challenge just because it is there. Whatever the reason, we often find ourselves with our eyes on the stars and our feet in the mud, savoring the urge to move up, to somehow push our head above the horizon.

My current mountain is SHHH. Just about four years ago, I began the climb. To me, it was something that had to be done. Now, the story of SHHH is developing into a great epic of our time. With a cast of thousands and a supporting staff which has both the will and the way, I find myself, in four short years, going from one high peak to another. Lifelines stretch to base camps all over the United States of America, Canada and Australia. And each day the mail brings news of many more who want to join our expedition. It gives us a feeling of exhilaration!

Thousands of us, who too often felt alone, are moving up — together. We breathe the heady air of accomplishment, of coping, of improved self-esteem. We belong — again — to community. We derive strength from each other and so continue to climb.

Yes, my friends, we have come a long way. As you read our gift to you, “Self Help in Action,” you will have a sense of having scaled your mountain. It will give you confidence to climb again and again, higher and higher, because we have much to give and there is so much to do.

Our congratulations to all of you on the fourth anniversary of SHHH (incorporation date: November 27, 1979).



# 1984

“He helped me envision a radically improved future for persons with hearing loss. A respected and valued mentor, motivator, colleague, friend, Rocky is one heck of a great mapmaker for life’s journey.”

**Patricia Clickener, Chicago, Illinois**

*January/February 1984*

## **The Struggle Toward Something Better**

A little humor goes a long way. Hannah Merker’s humorous treatment of a serious problem is welcome balm to tortured souls. Hannah’s pieces are often gems. She is one more example of how we can *LIVE* life in spite of the problems most of us bear. (“Bird Watching”).

So, too, with Joan Nielsen. Her story is in an even lighter vein — almost flip — but it’s hers. We can learn from both. (“So What’s So Hard About Hearing?”)

As for Bill Cutler — our man in Palo Alto — well, most of us with families will identify with his latest contribution to *Shhh*. (“Oh! Those Happy Holidays!”) Bill develops his story in the context of love and that is what sustains most of us.

The same theme of struggling toward something better is reflected in our two selections from SHHH Australia’s first newsletter. Charles Mackay comes to mind. In the *Old and the New*, he wrote:

“The smallest effort is not lost,  
Each wavelet on the ocean tossed,  
Aids in the ebb-tide or the flow;  
Each rain-drop makes some floweret blow;  
Each struggle lessens human woe.”

Happy New Year, all of you SHHHers!



*March/April 1984*

## **People First — Deafness Second**

When an adult loses his or her hearing, it is simply one more of life’s problems. How each of us handles that problem will be determined largely on the basis of personality and adaptation to life. That is why the word “People” is so important in our name, Self Help for Hard of Hearing *People*. SHHH focuses on people first — deafness second. We are

people who happen to have lost our hearing. The more we can expand our human dimension, the greater the chance we have of coping successfully with hearing loss.

Our story in this issue, “A Holistic Approach to Hearing Loss?”, reflects our belief that when a life event is seen as a challenge, we can cope. But when the same life event is seen as a crushing blow, helplessness and depression negate effective coping. We see a positive attitude as basic to a holistic approach.

Once the mind grasps the need for change or a readjustment and is open to information on how best to effect such change, there is a good chance for successful handling of the problem involved. Then, the various aspects of a holistic approach can be integrated into an individualized method.

We concede that our treatment of the holistic approach is somewhat superficial. Obviously, we have left a lot unsaid and some areas were not even touched upon. Our reasoning is that the basic point of departure in this field is attitude. If we can persuade even a few people that they can best help themselves by fostering a positive attitude and using the considerable support structure of an SHHH Chapter, we think we will have made an impact.

By taking responsibility for their health in its broadest sense, people discover new meaning and fulfillment as they participate along with the best of medical science in maximizing their health. But, when doctors do not encourage such participation, Norman Cousins sees the surge toward consumerism in medicine as “turning people against the system of elaborate referrals and the promiscuous use of medical technology.” The anxieties, the fears, the loneliness that we take to the physician’s office are compounded if there is no personal interest, no rapport between our doctors and ourselves. With the increased technology and specialization in medicine, people feel left out of the process. We are treated like things. We are seldom listened to. Too often, when doctors talk, they talk *about* us, not *to* us. Assertiveness, too, becomes part of the holistic process.

“If you are not part of the solution, you are part of the problem.”



*May/June 1984*

## **Expanding Horizons — Internationally**

Marcus Aurelius said it. “The universe is change; our life is what our thoughts make it...Observe always that everything is the result of a change. And get used to thinking that there is nothing nature loves so well as to change existing forms and make new ones like them.”

Change, passages, growth — at any point in life we can decide to broaden our horizons. A simple fact is that while we all live under the same sky, we do not all have the same horizon. So, if you are in the market for growth, *now* is a good time to buy!

By the time you read these words, several hundred of us will have gathered in our first international convention. Participants from more than 30 states, Australia, Canada and Israel, will have made new friendships, contributed to panels, tested equipment, engaged in workshops and in rap sessions, questioned industry representatives, elected a

new board of directors, won a variety of great prizes, and, in general, enjoyed ourselves thoroughly.

Shared experience leads to shared responsibility. And that is the real significance of Convention '84. SHHH members will have had an opportunity to come together to experience a national movement and then to participate in shaping the future of that movement. We know what it means to feel alone — to be alone. We know the joy of finding, talking and working with other SHHHers. We feel a great sense of accomplishment when we form groups and chapters.

Now we will find joy in sharing on an international level. We will see potential for SHHH that goes far beyond our chapter boundaries. Yes, it's time to expand our horizons. Welcome to an international movement of hard of hearing people. We hope you will become increasingly involved. Together, we can make SHHH great!



*July/August 1984*

## **Sharing Help, Hope and Happiness in Chicago**

SHHHcago! Convention '84 was so successful we are all ready to go again! Well — almost. An organization our size, with no paid staff and no government money, has to have a lot of pizzazz to attempt something like SHHHcago. We did it! We did it with hard work, detailed planning and help from a lot of people.

Close to 300 people registered for the full convention. Another 100 came for one day, or to visit the exhibits, or to attend Friday night's "Sharing Happiness" entertainment. Adding our valuable volunteers and the generous people in the exhibit hall, we had close to 500 participants in Convention '84.

Feedback from every aspect has been very, very positive. In fact, many members were ecstatic about their experiences. A quote heard often was "I almost made the biggest mistake of my life. I almost didn't come."

But Mary Irvine of Camden, Maine, summed it up best when she observed:

"The most incredible thing at Chicago was that never did I observe any speaker or participant to override the interest of any individual slower to hear or understand, in the interests of the larger group; nor did I observe even a tad impatience with the slower ones. You promised that no one would be left out, and it was so, down to the most flickering nuance."

That high praise could only be the result of close cooperation among SHHH, professionals (doctors and audiologists), and manufacturers (and others in sales or services to hearing impaired people).

Many professional people participated at their own expense. None received stipends for presentations. Many manufacturers donated items for our raffle, banquet flowers, program costs, the keynote speaker's travel costs, and so on. And seven companies provided us with assistive listening devices and systems for all of our workshops, general sessions and entertainment, at no charge to SHHH! Without their cooperation we could not have held Convention '84.

Dr. Winifred Northcott handled arrangements for oral interpreters (two were sent from Rochester, New York, by Dr. William Castle, president of the National Technical Institute for the Deaf). Sr. Alverna Hollis, executive director for the National Catholic Office of the Deaf, arranged for sign language interpreters. Both groups were very helpful.

And so, we thank you all! We implemented our theme “Sharing Help, Hope and Happiness.” SHHH brought it all together with you!



*September/October 1984*

## **First Survey of SHHH Members**

Surveys are useful to give us certain facts about a variety of categories, issues and concerns. Organizations use them to learn more about their strengths and weaknesses, to plot future courses of action and to keep their leaders in touch with reality.

But surveys are good only during the period they are taken. Rapid change affects surveys drastically. For example, in the SHHH survey of six months ago (reported in this issue), the average age of respondents was 62. Since that time, we have had many younger persons join, including young parents of hearing impaired children. Our geographic coverage at the time of the survey showed 63 percent of our members living in 11 states, and 37 percent in 39 states or abroad. But that too has evolved in broader terms.

The survey shows how difficult it is to build a national organization which includes all age, ethnic, and income groups. It defines areas to which we must reach out and bring help to hearing impaired people: the workplace, schools and the home itself.

The educational level of our membership is high. This has impact on how we talk to you, what we put in this *Journal* and what kind of chapter development we can expect.

Almost 40 percent of those responding had personal income of more than \$20,000 yearly, but another 35 percent were in the poverty range. Obviously we have to provide as much service at as little cost as possible. Another 20 percent have more than \$30,000 personal income and can afford to help SHHH survive and grow.

There were some surprises in the survey results (rates of progressive loss as opposed to sharp loss accompanying old age was one) and there were some results that were expected. Even more interesting to our readers will be the second report dealing with the adjustment process as described in rich detail by many of you. We hope to have all that available early in 1985.



*November/December 1984*

## **Language and Attitudinal Barriers: The SHHH Logo**

Our corporate birthday is in November. We are five years old — and counting. Congratulations! Instead of reciting a litany of our many accomplishments, let me dwell on something of fundamental importance in which we are still weak. The subject is language and attitudinal barriers. We are *people* — not things!

In the past 30 years, most people have learned to stop using the common pejorative terms applied to blacks, Jews, women and other previously repressed groups. Not so with disabled or handicapped citizens. Among the general public and media, as well as in professional rehabilitation literature, certain pejorative terms are still in popular use. Our language reflects our attitudes. June Walsh's article in this issue about the experiment with the definition of "deaf" in several languages, illustrates that clearly.

Specifically, regarding "the hearing impaired," SHHH takes strong exception to the absence of the word *people*. "Hearing impaired, deaf, hard of hearing," are all acceptable as adjectives. Their use as nouns is *not* acceptable. Our name is "Self Help for Hard of Hearing *People*." SHHH is a logo. It does not mean "Self Help for the Hard of Hearing." We are people first — hard of hearing second. We are people who are hard of hearing. It is very important that we get that straight. To be treated or to treat ourselves as inanimate objects ("the deaf" or "the hard of hearing"), is to convey a separate and inferior status.

We should not be participants in continuing this condition of negative attitudinal barriers — we who claim to work toward removal of such barriers. We should not hesitate to correct anyone who uses pejorative expressions toward others, particularly hearing impaired people. As we have said many times, "we have only lost our hearing — not our humanness!"

Happy birthday all you people!



# 1985

“We found ourselves in the company of a man of such incredible vision that even as he spoke of a mission which might have been impossible, we knew there would be help and hope for us and our child.”

**Carolyn Crawford, Chicago, Illinois**

*January/February 1985*

## **SHHH is Growing, Growing**

We hope you all enjoyed happy holidays throughout the Hanukkah and Christmas season. SHHH was undergoing some major changes during that period. We are now reasonably well settled in our new office space and we are very grateful that everything went so smoothly. But the really BIG news is about this *Journal*. A 50 percent increase. Changes in format and addition of new sections have been made without losing the down-to-earth style or affecting the highly relevant content.

Such major expansion is always risky. Increased size affects my ability to continue getting the magazine out on schedule. Gone are the days when I could plot the *Journal* in my head and actually put it together over a weekend or two. Now, planning, researching, writing, and editing are required well in advance. More time is needed for typesetting, proofreading and layout. And more material is needed from you!

Increased size and weight affects printing and mailing costs, the quality of envelopes we use, and the amount of storage space needed for a full supply of *Journals* for members who join throughout the year. Expansion of the *Journal* places additional strain on our financial position. But it was necessary.

As the only national magazine for hard of hearing people, we are under constant pressure to provide more and more information to our readers. There is no lack of information on the subject of hearing loss; the problem lies in getting that information into the hands of the consumer. Our press run is only 15,000 copies and we understand that the “pass around” value of *Shhh* is high, but that is still small when we know the need. Millions of hard of hearing people have never heard of SHHH or its *Journal*. The thousands we have “found” are most grateful for the information provided. You can help by talking or writing to people you know who are hard of hearing and who could benefit from SHHH. You may even wish to give them a gift membership in order to get them started.

And speaking of helping people, examine carefully our publications order form. There are many exciting articles you may have missed. Now is the time to order them.

As a self help organization, we are primarily indebted to our members for survival. We need your submissions (stories of coping, your inventions, how you get along at work, technology you use, etc.) We need your financial help. And above all, we need your enthusiastic response to our philosophy that we have only lost our hearing, not our humanness. Make no mistake, it is *you* who sustain us!



*March/April 1985*

## **Become Healers...and Heal Yourself**

Many of us are hurting. In today's world few can escape. It becomes a matter of degree. I often learn from our three-year-old grandson. Recently, David ran to his mother and said, "Daddy hurt me." His father quickly responded that he had not hurt David. In fact, he had not even touched him. David looked his father squarely in the eye and said, "You hurt me when you yelled at me!" His perceived hurt was real.

When we look at the face of Mother Teresa of Calcutta, we see beauty in goodness, but we also see pain — hurt. And in a glance we understand that "to touch a tortured age, one must absorb its pain." She is not only caring, she is feeling and sharing the pain of those she serves.

Ahme (my wife) works as a chaplain to dying patients and their families in a hospital setting. I know, the minute she walks in the door at night, if one of her patients has died. She is wounded because she has absorbed some of the pain. Through it, she helps heal the family.

Those of us who hurt deeply because of our loss of hearing and what it does to us, have very urgent needs to be satisfied. But what we sometimes forget is that in our experience of pain we have much to offer. Turning inward, self-pity, withdrawal, bitter feelings, all tend to diminish us as human beings. We need to realize that in our pain, we can become healers.

Healing is a gift of the wounded. We become increasingly sensitive — to our needs, and to the needs of others. By knowing, from experience, what hurting means, we can help alleviate it in others. With the experience of pain, life changes. Our priorities often shift. We focus more on meaningful things and we become more aware of each other, a prerequisite for healing.

We see it happen at chapter meetings. "I have a severe hearing loss. It continues to be a problem, particularly at home and at work. But in our SHHH meetings I have met others with more severe hearing impairments. By sharing my own problems and experience with them, by helping in small ways, by showing a genuine interest in them, I have contributed to a lightening of their burden and an improvement in their situation" Sharing. Helping. The beginning of a dialogue and a new relationship. It brings hope and leads toward happiness. Think about it, all you SHHHers — *you* can be healers! And, in the process, you heal yourself.



*May/June 1985*

## **Staying on the Job**

When I was 45 years old, I made the decision to retire at age 50. (Under the Central Intelligence Agency's [CIA] retirement program, certain categories of employees could retire at 50 without reduced annuity.) My stated reason was that I would still be young enough to do something else — and I had several ideas of what I wanted to do. By the time I actually reached 50, several things had happened to reinforce that early decision, but for different reasons.

I had gone from severely hard of hearing to profoundly deaf. We were stationed abroad and my return to Washington would have required frequent use of the telephone with many high-level people. The price I would have to pay for remaining in a fascinating career had climbed too high. I left without regret — only thankful that I had been able to handle the job up to that point.

In my association with SHHH, I see many young, talented people who left their jobs (or were forced out of them) due to hearing loss. What can be done? I think a great deal can be done. First of all, many people who leave their jobs voluntarily are unaware of the progress being made in areas of workers' rights, educational programs, technical developments and dialogue between employers and employees which help keep the person in his or her position despite hearing loss. Secondly, there is some movement in the direction of changing jobs within the same company or organization, so as to accommodate the circumstances of the employee. Thirdly, much can be done to develop new skills which can result in improvement of the employee's situation (for example, a secretary who can no longer use the telephone moves into word processing or other computer-related activities).

Information is essential. But *what we do* with that information is equally essential. In this issue you will find the word "assertiveness" mentioned in several different places. The assertive person learns what options are available, then selects those most appropriate to his or her needs — and *acts* on them.

No one can help us fight our battle until we make the basic decision to help ourselves. Once that major step is taken, the way is open to improve our lot. Believe it or not, there are many people willing and ready to help us communicate effectively if they know what it is they should do. Isn't it time we began to tell them?



*July/August 1985*

## **“Between Two Worlds” The Ambiguity of Partial Deafness**

One of the major reasons for the existence of SHHH is my belief that partial deafness causes significant problems for a person. Dr. Michael Harvey, a clinical psychologist,

agrees. In his article, “Between Two Worlds,” he explores this concept in some depth. Dr. Harvey describes the problem of being “pulled” in opposite directions at once. Being stuck in the middle, not knowing where you should, or want, to go, is stressful.

I remember writing in 1979, “I realize now that I exist in a twilight zone, unable to hear in the sunlit world of sound, yet not enveloped in a night of silence. I realize that the difference, the ambiguity, is my problem.”

Ambiguity, uncertainty, confusion, all create anxiety. When we are anxious, worried, concerned about our situation, we are usually on the defensive. Even the most positive among us can have doubts.

That is why it is so constructive to meet in community — at chapter or group meetings of SHHH. Reassurance, affirmation, encouragement, are all wonderful tonics for the hard of hearing person who has yet to work through the problem and establish a niche. We need to find the place where we are comfortable. I hesitate to use the word “identity.”

Unlike persons born deaf, some of whose first language may be sign language, thus affecting their linguistic and cultural outlook, persons who lose their hearing as adults are already part of a hearing culture. Our identity is not a product of hearing loss. We need to make adjustments, to do things differently, but few of us seek a new identity.

What we need is association with others facing similar difficulties and the reassurance that we are still the unique, wonderful human being we always were. Through strength derived from such associations, we then proceed to find new ways of handling our problem. Actually we are not hard of hearing people, but people who are hard of hearing. We must seek an adjusted place in life with that understanding

While writing this, I wandered through a consideration of my own identity. Here is what came out. I am human — a child of God. I am unique. I am endowed with certain gifts. I have inherited certain traits and tendencies, and acquired certain skills. My initiative and drive result from a combination of heredity and environment. I am fortunate. I am Rocky Stone, and with the sum total of what I am, I cope, as best I can, with profound deafness, severe tinnitus, and partial blindness.



*September/October 1985*

## **Coping and Stress Management**

Turning the world on! Let’s get with it! Go for it! Get in the swing! These are all slightly different ways of expressing a positive action concept. Essentially, this type of speech means that we should involve ourselves in life. Our lives! We should move into an active phase of behavior which enhances our life situation.

For hard of hearing persons this means learning and using whatever we need to keep us in the mainstream of life. It means developing a greater awareness and understanding of the implications and consequences of hearing loss. It involves conscious effort in building interpersonal relations; in cooperating at group levels; and in sharing our talents confidently, assertively, with the community at large.

Stress management is a popular subject these days. Everyone experiences stress in some form or another. Things that place me under stress may not bother you and vice versa. But there is one universal stressor — the breakdown in communications. That's what happens when loss of hearing occurs. Starting in this issue we will run a series of articles on stress management by Dr. Sam Trychin. We will share with you the methods, contents, and results of a course conducted here at SHHH headquarters by Dr. Trychin. It was quite an experience.

From such experiences, hard of hearing persons can adjust to their circumstances of hearing impairment. They can learn how to "get with it." By learning to recognize stress for what it is, its symptoms and means of control, we focus on it in a highly personal and specific way. It becomes easier to handle. We grow with the experience and we become increasingly confident with each successful application of our knowledge. Confidence is something badly needed by most hearing impaired persons. Building confidence is something SHHH does with its members.

As our confidence grows we are more able to help others. Thus, self help evolves into mutual help and then into potential for community service. We become whole and we rejoice in our new feelings of self-respect. So, turn the world on, all you SHHHers, and let everyone share your glow.



*November/December 1985*

## **SHHH: From the Little Things Come...**

Alice Marie and I attended the Eucharistic Conference in Nairobi, Kenya, during August. Among the luminaries present were Pope John Paul II and Mother Teresa of Calcutta. I was surprised to hear criticism of Mother Teresa. It boiled down to what some feel is her failure to address the root causes of problems and, in some cases, actually aggravating a problem by her approach.

For example, in Indian culture, the family is supposed to take care of its own. By relieving some families of this responsibility through her activities, Mother Teresa, they claim, undercuts a strong and healthy aspect of Indian culture. Moreover, her efforts focus too much on little things rather than big things; for example, she treats the symptoms rather than the disease.

Maybe so. But I couldn't help wondering how many big things any of us accomplish while Mother Teresa is working on those little things. I was reminded, too, of the old saw that if we take care of little things, big things take care of themselves. But in reality we need people who work at both little and big things without the necessity to deprecate either.

That's what SHHH has been doing for almost six years. When we celebrate our birthday at the end of November, we can take pleasure in the realization that an effectively organized constituency is well underway; a constituency which can have great influence on the lives of millions of hearing impaired persons. While we have been doing that, a direct personal impact on thousands of hearing impaired people has occurred every day throughout 145 chapters and groups. The little things...a smile, a kind word, an

explanation, a touch, a demonstration, sharing experience, caring, all things that affect the human spirit. Yes, SHHH is building a solid base on a multitude of little things that in the near future will support that big and effective constituency.

We have much to celebrate. More so, when we realize that we've just begun. Congratulations and thanks to all you SHHHers! You are doing a grand job.



# 1986

“Rocky changed my life. The cochlear implant brought me back into the world of sound, SHHH brought me back into the world of people”

**Tommie Wells, Fort Worth, Texas**

*January/February 1986*

## **Expanding Collaboration with Professional Organizations**

How often have you heard someone say, “That’s music to my ears!” when good news is received? We, who are hard of hearing, sometimes dwell on the negative aspect of that condition. But, in fact, there is music all around us. The good news of expanded awareness; of our increased ability to cope; of the recognition by government, academia and hearing health professionals that partial hearing loss represents a problem that requires help and understanding, not previously accorded to it; and, of course, the good news of a newly-found courage and power in expression of the rights of hearing impaired people and the dignity of their humanness.

In six short years, SHHH has managed to include hard of hearing people in services which were previously exclusively for deaf people. We have negotiated a formal understanding with the Rehabilitation Services Administration, the National Institute of Handicapped Research, and State Vocational Rehabilitation agencies, all of which are now aware of the needs of hard of hearing people. We recently concluded a joint symposium with Gallaudet College which resulted in an examination of Gallaudet’s programs for deaf people. We recently concluded a joint symposium with Gallaudet College which resulted in an examination of Gallaudet’s programs for deaf people to determine where and how services to hard of hearing people may be included.

Our work with the American Speech-Language-Hearing Association and with the American Academy of Otolaryngology continues to develop respect and appreciation for SHHH among hearing health professionals. Soon, we will commence formal cooperation with the National Technical Institute for the Deaf — once again to expand services toward hard of hearing people. And, in 1986, we hope to launch a national hearing awareness campaign directed at our hearing friends.

How’s that for music? Truly, it’s all around us.



*March/April 1986*

## **Symbols of Hearing Loss: A Constructive Influence?**

For the past 25 years, researchers have provided ample evidence that a stigma is attached to wearing a hearing aid. Indeed, the history of hearing aids is an exercise in deception. The true function of hearing aids has been disguised by concealing the aid in canes, fans, pearls, glasses, or in some decorative element designed to fool the observer; *anything* to avoid letting others know you wear a hearing aid. Now, ultimately, we try to hide it within the ear itself.

Clearly, the stigma does not attach to the device but to the problem which requires its use — hearing loss. Wearing a hearing aid is open admission that one has a hearing loss. That is where the stigma is attached. Consequently, millions of persons who might profit from amplification fail to do so because of the socio-psychological barriers imposed by society and the hearing impaired person's acceptance of those barriers.

Hearing people who lose their hearing (most of us) are part of the hearing culture. We have the same fear of deafness and the same attitudes toward deaf people as hearing people. We must overcome this fear, embrace our deaf sisters and brothers, and help change the attitudes of our hearing friends.

The stigma attached to hearing loss is deeply rooted in Western culture. Until recently, the only method of dealing with it has been to hide it. Miniaturization of hearing aids is a direct consequence of consumer pressure. We have always been more interested in hiding the device than we have been in what it can do for us.

Stigmas don't go away. We have to do something about them. That's where symbols come in. A person wearing a symbol of hearing loss boldly states that fact publicly. By taking the initiative, the wearer of a symbol is in a position to constructively influence communication patterns with others. The wearer can keep his or her hearing loss in perspective and focus on humanness rather than disability.

In this issue we examine a 20-year old attempt to promote symbols of hearing loss in America. We need not be discouraged at the slow pace at which this process is moving. Cultural attitudes are not changed in short time frames. But, even if slowly, change we must. And we must change the attitudes of our hearing friends.

This is your challenge. Will you make an attempt to choose a symbol which you think conveys the message hearing impaired people want to convey to hearing people? Will you agree to wear and promote that symbol? No symbol will please everyone but if we cannot choose one in some numerical strength, we will continue to accept the barriers imposed on us by society. As long as we accept them we will never change them by complaining. In fact, as long as we accept them, we have no basis for complaint.



*May/June 1986*

## **IFHOH: What Do We Need for Travel & Entertainment**

The “Hearless Traveler” is finally getting some attention. In June, the International Federation of Hard of Hearing People (IFHOH) will hold its annual meeting in Rochester, New York. The focus of the meeting will be on devices and procedures (services, techniques, etc.) which could contribute to easier and more complete participation of hard of hearing people in travel, entertainment and hospitality industries.

SHHH members are participating in the planning for this meeting and SHHH will be represented. Representatives of the hotel/motel and restaurant industries will be there, as well as persons from the motion picture industry, radio, theater and television. Other travel-related industries are being sought for participation.

At the risk of drowning in paper, I invite each of you to send in your list of subjects to be addressed at the IFHOH meeting. We will cover such things as assistive listening devices in meeting areas, theaters, on travel tours, etc. Subjects such as compatible telephones in hotels and other travel-related areas, background music on television, quiet areas in restaurants, and other topics close to our hearts (and ears) will be highlighted. Nevertheless, I’m sure you have more. Here is your chance. Tell us about those things you need to make life enjoyable when you travel. Or, tell us why you don’t travel (fear — can’t hear the fire alarms in hotels; privacy — can’t hear the door knock and someone entering without your knowledge; convenience and enjoyment — you can’t function within the existing service structure).

What are your recommendations to those we seek to educate? Your participation in the best tradition of SHHH can help make this meeting even more significant. Then we, too, can become “Fearless Travelers.”



*July/August 1986*

## **SHHH: A Caring Family**

A friend of mine recently wondered aloud about my involvement with SHHH. “How is it,” he asked, “that a person with the broad interests you have can become completely immersed in such a limited subject as hearing loss?”

I assured him that hearing loss is not a “limited subject,” but one that impacts on all important aspects of the human condition. Not wanting to argue that, he proceeded to probe into “What makes Rocky run?”

“You must get a lot of satisfaction out of what you are doing,” he said. I agreed. “And you must get a lot of positive feedback — a lot of praise,” he continued. Again, I agreed. “So now I understand,” he concluded. I was not really sure he did.

While self-satisfaction and ego-gratification are certainly part of motivation, the real reason I and many others of us do what we do is a deep awareness of the hurt and pain

carried inside hard of hearing persons. If I can alleviate that hurt (or pain) even to some small degree, I'll keep pushin' along.

An example: Not too long ago I was speaking to a group in Denver. A young woman expressed her gratitude for SHHH and then, tearfully, described how many years of her life had been wasted because she had been told she had nerve deafness and nothing could be done about it. As she spoke, tears came to my eyes and my whole being ached for her. I looked at the others and I saw they, too, were feeling her hurt. There was no embarrassment for either of our tears, no need to apologize. Everyone was in tune with the moment. We were together — in more ways than one. That's SHHH!

We no longer have to hide out, ignorant of the damage we do to ourselves and those around us. We don't have to sit, lonely and depressed, wondering where love has gone. We no longer have to endure the anxiety, the frustrations, the anger, which keep us churning inside. We, as SHHH, are emerging as a huge caring family — working together.

SHHH is people — just like you and I. We all understand each other's problems. We are in need of each other. We have much to give each other. And in that exchange of gifts, a bonding of strength takes place which forms the base of SHHH.

This is the kind of togetherness you will find at its highest peak when you attend the SHHH Convention in August. Come, and let me thank you in person for fueling my drive toward service.



*September/October 1986*

## **Making the Grade: Excellence versus Success**

Our theme this issue, "Making the Grade," leads me to some basic observations about the difference between excellence and success. Thomas Boswell, a *Washington Post* sports writer, wrote a column on this subject, from which we can all benefit. He pointed out that "there is no substitute for excellence. Not even success."

They are not the same. "Success," Boswell said, "is tricky, perishable and often outside our control...Excellence is dependable, lasting and largely an issue within our own control." While success makes a poor cornerstone for life, excellence is the best of foundations.

Since we all possess both a desire for success and a love of excellence, where does the balance lie? When the going gets tough, what guides us? Success can burn up the person (or organization) who achieves it. Excellence usually feeds whoever has it. The pressure for repeated successes — especially in the eyes of others — can be killing and it poses a threat when others achieve it (the old "number one" syndrome). But the person fascinated by quality is invigorated when observing excellence in others, and copes with being surpassed, since he respects the quality involved.

Boswell thinks that such people remind us of the most rigorous teacher we ever had. "The teacher who showed us the agonies of patience that went into crafting a poem so precise in its choice of words that we could read it a hundred times over in 50 years and always find it powerfully true. The teachers, in other words, who taught us that love of

learning — for itself — and not love of grades, was the beating, enduring heart of education.”

That is what we strive for in SHHH — excellence. A continuous effort to improve ourselves and to help others by building a foundation that lasts; to show how life should be lived; to pass through the wins and losses of life, knowing, that in the long run, we will have left something that others can cherish.

“Making the grade” for us is our constant struggle to achieve excellence.



*November/December 1986*

## **Working Together: SHHH Convention at Stanford**

Together. The word has a nice sound to it — and important implications. We join together for some purpose — as in SHHH. We gather together for another purpose — as in our recent convention at Stanford University. In the latter case, the “we” constituted hard of hearing people, some deaf people, and hearing people. And what a display of togetherness that was! In addition to more than 80 presenters — most of whom are hearing persons — there were a number of people in the hearing health delivery system present as registered participants. Clearly, such a large and complex undertaking could not have succeeded without enormous goodwill and cooperation from our hearing friends.

Together means hearing impaired and hearing people, working to alleviate the plight of millions of others who suffer from hearing loss. Together means hearing impaired people and members of the hearing health delivery system working toward solutions to individual problems relating to hearing loss.

I have been impressed with the outstanding cooperation SHHH receives from hearing professionals. By coming to our convention (many at their own expense) and receiving no honorarium for their services, these people were telling us that they want SHHH to succeed. Certainly our success will benefit professional care providers, but that will take time. Meanwhile, many professionals are busy contributing to that success.

Another encouraging sign from the convention is that those professionals attending, explicitly stated that *they* learned a great deal from the experience. Doctors, audiologists and hearing aid specialists throughout the land are telling their peers how impressed they were with *you*! Obviously it’s a step forward and one more indication of how we can do far more *together* than we can with a “we versus they” mentality.



# 1987

“No one, to my knowledge, has gained more from SHHH than I have, nor owes more to its founder, this extraordinarily giving person who has touched so many lives, for the better.”

**Manell Brice, Arlington, Virginia**

*January/February 1987*

## **From Loneliness to Solitude to Reaching Out**

When one considers that to love is to risk, we put fear into perspective. When we openly manifest our love for someone, for each other, we make ourselves vulnerable. We risk being hurt in a variety of ways, among them — rejection. But we take that risk — in spite of some fear — because we know, to paraphrase an old song, that the greatest thing we’ll ever learn, is just to love and be loved in return.

Fear inhibits. As Hamlet said, it does make cowards of us all. So when we begin to lose our hearing (and don’t understand what has happened), we become frightened. We are afraid of further hearing loss. We are afraid of losing our job and our friends. We fear appearing ignorant. Most of all, we fear being different. In our society, difference is often the beginning of prejudice — whether it’s being black, poor, handicapped....

To overcome fear, we have to move from loneliness to solitude — from that which is imposed on us to that which we seek. This requires a searching of our innermost being and an ultimate realization that we are never alone. It also leads to an equally important movement, described by a Dutch writer, in which our hostilities can be converted into hospitality. Finding ourselves can lead to a reaching out to the many strangers estranged from their own past — strangers who themselves search for a hospitable place where life can be lived without fear.

SHHH offers that. We offer an open and hospitable space where strangers can cast off their strangeness and become our fellow human beings. We want to expand this capability where a free and fearless space is created in which fellowship can be formed and fully experienced. Thus, we give each other a chance. We accept each other for our humanness, not for who we are or what we do. And through this acceptance of ourselves and others we overcome our fear.



*March/April 1987*

## **Taking Charge of Your Life: Your Choice**

What does “taking charge” mean to you? What images do you associate with the term? A Marine sergeant? A new supervisor? An executive? A top-flight coach? A tough teacher?

I’m sure that many of us would say that the term “taking charge” implies a taking over of authority. But that’s only half of it. The other half is that whoever takes charge assumes the responsibility for what will happen in that area. Taking responsibility for our lives means taking charge of our lives. It is a role each of us should strive for.

Self-doubt, often caused by hearing loss, works against our efforts in this regard. Loss of hearing changes our perceptions of ourselves and of others. The impression that we are no longer capable; the frustration of just getting through one day; the hurt (and humiliation) of trying to function in a hearing world; all of these lead toward a negative condition. We sometimes forget that we have only lost our hearing — not our humanness.

Aldous Huxley has good advice for us. He said that of all the things in the world we would like to see changed, the only one of which we are capable of changing is ourselves. We can take charge of our lives, accept responsibility, confront our hearing loss and make adjustments. That series of acts describes many of you SHHHers. You know as well as I do, that the results are worth far more than the effort.

Age has little to do with ability. You have a choice in your life. If you exercise that choice, you take charge of your life. If you choose not to make a decision, remember that is your decision. And if that’s what you want, it’s okay.

Those who “take charge” seem to feel better about themselves as a result. Realizing your potential and acting on it is your goal. Our job is to help you do it.



*May/June 1987*

## **Jobs: Interviews and Competition**

For some, competition is the spice of life. For others, it’s a bit of hard gruel. In the workplace, job competition with others means that all competitors must be qualified to have a chance. The qualified person with a disability must still face the subjective evaluation of the interviewer who often decides (rightly or wrongly) what the disabled person can or cannot do — regardless of objective evidence.

Just arranging an interview by phone can be difficult for many hard of hearing persons. Missed words, names and dates or an inappropriate response can lead to an aborted telephone conversation precluding a face-to-face interview.

Frank discussion of a hearing impairment, along with a statement of what one’s needs are to function effectively, can sometimes be detrimental to the purpose of getting the job. That’s the down side.

The up side is this. If we can appreciate the extraordinary potential of the human spirit and recognize our own worth in the context of just being human, we may be able to exude a dignity and confidence in ourselves which overcomes the most skeptical of interviewers. It is very important to remember that how we feel about ourselves influences how we act. That, in turn, influences how others feel about us and how they behave toward us.

Much of our competition is within ourselves. We have all heard of the “I — I think I am,” the “I — I want you to think I am,” and “the real me.” People with disabilities or “handicaps” must look deep within themselves for the mature development of their human identity. It is a difficult process. So much so, that once you win against such great odds, competition in other areas seems mild.

The ability to learn who we are and to be comfortable with that identity, enhances our ability to compete successfully in many walks of life. That kind of mature accomplishment is reflected in our behavior and goes a long way in reducing negative, subjective evaluations of us by others.

Obviously, there are many different factors and conditions that separate those who achieve in spite of all the odds from those who do not. But one thing is certain, you will never know how much you can achieve until you try.



*July/August 1987*

## **Trust and Confidence: In Our Eyes and Others'**

I grew up without much parental involvement. By the time I was seven my father was gone. My mother worked and our time together was limited. Nevertheless, her impact on me was profound. With keen insight, good judgment and excellent common sense, my mother instilled in me some major life values. One was trust.

Her approach was more effective than original. I recall her asking me, when I admitted to taking something that didn't belong to me, “Rocky, how can you trust others if you cannot trust yourself?” The implications of that basic thought struck me with such force that it has remained with me since.

Repeated scandals among government, business and religious leaders erode trust too often. We generalize from these specific events to broader elements in society. Some persons may even use these events to justify their own inadequacies. The fact is that there are many millions of persons worthy of our trust in communities across the United States of America.

SHHH comes to mind. The degree of trust we place in one another continues to light our darkest days. Confidence. Reliance on each others' integrity and friendship gives new hope to thousands in SHHH. In reaching out to each other, we rekindle that flame so necessary for effective community trust.

And if, because of weakness in the human condition, that trust is violated occasionally, it should reinforce our own determination to become increasingly trustworthy — in our own eyes and in the eyes of others.



*September/October 1987*

## **Promoting Awareness — the Self Help Way**

SHHH will soon celebrate its eighth birthday (November 27, 1987). Conventional wisdom says that it takes 10 years to establish a national organization in the United States. While not yet a household word, SHHH is already widely known among organizations concerned with the problems of hearing loss. And yet, millions of individuals with hearing impairments have never heard of SHHH. It's a big country.

So often people ask me, "What are you (Rocky) doing to change the attitudes of hearing people about hearing impaired people?" or "What is SHHH doing to develop greater awareness of the problem of hearing impairment among our hearing associates?" It's time to change the question to "What are *we* doing in those areas?" We are all, every one of us who has a hearing impairment, personally liable for educating the public.

What do you think would happen if each and every one of us wrote a letter to our local newspapers and radio/TV stations, telling them about SHHH and its many accomplishments in a scant eight years? Would we celebrate our birthday with a national roar — and, a surge of new members? Maybe.

Or, what if each one of us pledged to introduce just one other person to SHHH during the month of November. Unrealistic? Why should it be? A little effort from each one of us can add up to a quantum leap in doing what we do best — helping people.

In August, we held a symposium on philosophy in order to obtain a consensus among the founders of SHHH as to what we are, what we want to do and how we want to go about it. We reaffirmed the self help basis for SHHH and the approaches that flow from that philosophy. In choosing the self help way, we have made a choice.

We have decided not just to live, but to live fully. We are engaged in activities which further our own development and which enable us to provide more to others. Choice and conscious endeavor. Listen to Thoreau: "I know of no more encouraging fact than the unquestionable ability of man to elevate his life by a conscious endeavor." We are becoming, becoming and becoming.

If you have not yet made this choice, *now is the time!*



*November/December 1987*

## **A Season of Hope**

We are entering a season of hope. That uniquely American celebration of Thanksgiving is closely followed by the wonderful Jewish festival of rededication of the temple. The season culminates in the Christian commemoration of the birth of Christ with its message of peace on earth and goodwill for all.

Right in the middle of that season, SHHH celebrates its eighth anniversary. It fits in well. SHHH is a symbol of hope.

In our eight years of existence, I can't tell you how many people have told us that SHHH has saved their lives, but there are many. Not only saving lives, but mending them, putting families back together, and pointing the way toward a future — of hope.

Another element of this season of hope is the bicentennial celebration of our Constitution. The United States is the only country in the world with a political document spelling out, not only the right to life and liberty, but also the pursuit of happiness. Many of those who write about happiness list at least three essential ingredients for a happy life: faith, someone to love, and the dignity of work. I would add hope.

If the winds of fate have buffeted our faith in the turbulent times of our generation, they have also filled our sails (or souls?) with hope, to expect something good with a reasonable chance of achieving it. Hope is held out to us by our traditions such as the holidays we are about to celebrate, by the remarkable survival of our Constitution as a living document, and by catalysts for change such as SHHH.

The self help concept means that an individual has made a conscious decision to change his or her life circumstances for the better. Only the individual can make that decision — that's self help in its most elemental form. Once the decision is made and implementation of it has begun (in our case, joining SHHH, reading the educational materials, joining a chapter), then process broadens.

Self-esteem and confidence rise through knowledge and shared experiences. We grow beyond the independence of that basic decision to help ourselves to the mature realization that we all need each other, that we are interdependent. Then we become involved in mutual support. And finally, we are able to look beyond our own problems and work in a community where others need our help. We become a sharing community. What better basis can we have for hope?

# 1988

“From Rocky I learned ‘people come first, then the SHHH organization’ — that SHHH does things *with* people, not *for* them.”

**Howard Potrude, Kalamazoo, Michigan**

*January/February 1988*

## **Alternative Communication**

Alternative communication simply means that when your preferred mode of communication breaks down you switch to an alternate mode(s) in an effort to continue the communication process. When hearing fades, you are primarily concerned with receiving and understanding communications as well as making an adjustment to new life circumstances. If you can benefit from amplification (most hard of hearing persons can), there is a whole range of hearing aids and assistive listening devices from which to choose. Amplification is the least intrusive form of alternative communication. It generally helps develop speechreading skills and it demands little more than patience and understanding from those with whom we are trying to communicate.

When amplification or a combination of it with speechreading fails, we may have to resort to total communication, speechreading and Cued Speech, speechreading and finger spelling; or speechreading, Cued Speech, or sign language alone. Cued Speech requires that you and your associates learn the cues (a 20- to 30-hour investment), and sign language requires that you and your associates make a year-and-a-half to two-year investment in learning the language, and then maintain it.

Less than one percent of persons who lose hearing later in life ever learn sign language. Yet it is the most precise and reliable of the three modes discussed. Apparently the investment in time and energy is too high at too late a time in most persons' lives.

In order to learn all you can about the various types of alternative communications, you should attend the SHHH Convention in Rochester, New York, in June. This issue of *Shhh* contains a registration form for the convention. Fill it in today. What you learn there could change your life. It has for many others. Assistive devices and several forms of communication modalities give you the opportunity to choose that method with which you are most comfortable and which best suits your circumstances.

Get back into the mainstream of life, socially, at work, and during your leisure time. Come to Rochester and let us help you change your life! You will even enjoy the process. Just “Picture Yourself in Rochester, Where the Focus is on Communication.”



*March/April 1988*

## **Cooperative Ventures**

We cannot do everything, but with cooperation almost anything can be done. Ten years ago, leaders of the National Association of the Deaf and the Alexander Graham Bell Association for the Deaf were barely on speaking terms. Today, the executive directors of those two organization work side by side as co-chairs of the Council of Organizational Representatives (COR). Ten years ago, hard of hearing people had no national organization. Today, SHHH represents them in COR. Deaf and hard of hearing people are cooperating in a variety of ways in several different forums. No one would have predicted that ten years ago.

Cooperation, working together to achieve a common result, takes many forms but requires specific attributes. In the case of COR, strong differences of opinion regarding methods of communication (sign language or oral) are submerged in the stronger tide of advancing the interests of *all* hearing impaired consumers. Openness to another's point of view (even if you disagree with it) and an ability to see beyond one's own agenda are essential for cooperation. As COR's membership grows (and with that, a diversity of issues), the organization will be sorely tested. From what we have seen so far, COR is well positioned to face the challenges ahead of it.

Another type of cooperation is that between SHHH and three government agencies described in this issue: the Rehabilitation Services Commission (RSA); the National Institute on Disability Rehabilitation Research (NIDRR); and the Council of State Administrators of Vocational Rehabilitation (CSAVR). Here the areas of cooperation are broadly described with each participant having specific responsibilities which can be renegotiated as experience warrants.

A form of international cooperation is illustrated by our membership in the International Federation of Hard of Hearing People (IFHOH), a loose association of organizations from around the world. We will send four delegates to its Congress in July 1988.

All these examples point to one thing. Divergent points of view emanating from widely separate geographic locations and historic experience are converging on one point: satisfying the needs of the hearing impaired consumer. Yes, SHHHers, we are making a difference.



*May/June 1988*

## **“Picture Yourself in Rochester”**

Many of you have heard me talk about how we are meant to live in community. Hearing impairment, particularly late onset, works against that basic need. The retreat, and frequent withdrawal, from society by those who are hearing impaired is due to the

lack of adequate information about their condition and the absence of a strong support structure.

A dramatic reversal of that feeling of isolation is what you will discover when you “picture yourself in Rochester” at the 3rd International SHHH Convention. More than 1,000 persons from 35 or more states and five countries will converge in community. (More than 400 had registered by mid-April!)

Most of the attendants will be just like you — persons with hearing loss. They will be in Rochester for several purposes: to learn from the varied educational workshops and to absorb information from our distinguished speakers; to have hands-on experience in the best technology available in the hearing health field; and to participate in our movement to “Make Hearing Loss an Issue of National Concern.” But most of all, they will be there to share ideas and experiences with you, with each other — in community.

Sharing in a relaxed environment, where no explanations or apologies are needed, where your feelings of being defensive (and sometimes feeling hopeless) are transformed into feelings of joy and hope...*that* is what you will experience in Rochester. This feeling of belonging and being accepted as a human being (regardless of what you do or what your rank or social status might be), is crucial to self-image and self-respect. You will find yourself enhanced by your involvement and you will return home feeling good about yourself. You will develop greater confidence and increased capability for helping others in circumstances similar to your own.

We want you in the picture. You need to be there. So “Picture Yourself in Rochester.” You are important to our community.



*July/August 1988*

## **The Shared Pain of Fire**

All we could see was black smoke billowing from the roof and streaming from our office space. The rapid accumulation of 15 fire trucks, three ambulances and numerous police cars heightened the drama.

We stood, in a small group, diagonally across the street, trying to control our emotions. SHHH appeared, literally, to be going up in smoke, but the situation was confused. We couldn't see much fire (the blaze stayed in the center of the building). Perhaps the damage wasn't so bad. And yet...why so many fire trucks? Why that seemingly endless stream of thick black smoke from all five of the huge gaping holes which once contained our picture windows? (The windows were all broken by firemen in order to reduce the pressure inside the building and, ultimately, that saved the roof from collapse.)

It was shared pain. Each one of us feeling deeply about the disaster we were witnessing and worrying about the impact on the others. Finally, the anguish of inspecting the ruined offices; the sadness in picking through junk piles, looking for things which might be saved; the dawning of reality (three months or more before our return would be possible); and then, gradually — acceptance.

No one was hurt (except for our internal turmoil). The damage is to things. We lost a lot — in time, convenience, material things and money (insurance is unlikely to cover everything). There are so many intangibles in our operations. “Replacement value” is not always very appropriate.

And yet, what came of this experience was renewed commitment and determination from all staff members to meet this challenge. With that came a deeply emotional reaction from members, clearly reflecting that SHHH is perceived as a lifeline. We mean something important to one another. And we mean something to hearing people! Many offers of furniture, computers, etc., came from persons and organizations having nothing to do with hearing loss. So the experience, as most things, had two sides to it — the negative and the positive. In the long run, the positive side will prove more meaningful and I can paraphrase a famous line: neither fire, nor smoke, nor water can prevent SHHH from achieving its anointed success.

Hang in there, SHHHers — and thanks.



*September/October 1988*

## **Keeping Older Persons in the Work Force**

Because of the large numbers involved in our aging population and the implications those numbers have in economic and political terms, we hear a great deal about Americans growing older. In addition to being talked about, older persons are being “targeted,” sought after and talked at as policymakers perceive the shift in power brought about by the aging of America. Parallel with all these developments, a more favorable image of the older person is emerging in our society.

Organizations like the American Association for Retired Persons (AARP) and the National Council on the Aging (NCOA) have done a tremendous job in bringing issues important to older persons into the public forum. At the NCOA’s 38th annual conference, Robert T. Jones, U.S. Assistant Secretary of Labor, declared that the “bottom line” in today’s labor market is that employers need older workers now and will need them more in the future. Demographic changes are reducing the proportion of younger workers in the labor force. The message is clear. Keep older persons in the work force!

It is ironic that while this message goes forth, a contradictory trend is ignored. More and more persons are losing hearing after 40. Although some lose their jobs when hearing goes, most relinquish their jobs early rather than fight the problems created by hearing loss for an older person in the workplace. Consequently, at a time when we need to keep older persons in the work force, some 25 percent lose their hearing and a large proportion of that 25 percent leave the labor market.

We can help reverse this trend by educating employers (as well as hearing impaired persons) as to what is available to keep workers productive in spite of hearing loss. SHHH helps the person cope with problems created by loss of hearing; it helps employers understand what things like assistive listening devices and systems (ALDs) can do to keep a competent employee functioning; it develops awareness among the public and in our legislative bodies, of the nature of the problem and its remedies; in short, SHHH

thinks that older persons, with or without hearing loss, have an important role in our society — now and in the future. It's all in knowing how to play that role.



*November/December 1988*

## **Educating Employers and Co-Workers**

The right to work is often circumvented by circumstances. This is particularly true of the person whose hearing deteriorates while still in the work force. A combination of denial, fear, anger, frustration and no real understanding of what is happening, inhibits candor. Too often the job is abandoned by default.

It is usually difficult, for most people, to openly discuss personal problems. It is even more difficult when the person with the problem perceives it to be an embarrassment. The impact of hearing impairment on adults who acquire it is predominately negative. This negative impact can fuel a vicious cycle. Embarrassment, self-blame, poor self-image, inhibition, depression and ultimately, voluntary departure from a job. The good news is that it doesn't have to be that way.

As SHHH gains experience with employers and hearing impaired persons in the workplace, we continue to find that the problem is lack of information on the subject and poor communication between the parties. In a small way, our video showing how assistive listening devices can improve productivity of hard of hearing persons is catching on. This educational film, designed to help employers understand the problem of their hard of hearing employees, is just one effort to place accurate information in the hands of employers throughout the United States.

In addition to educating employers about such problems, the hearing impaired person must educate specific employers about his or her particular problem. This issue of *Shhh* contains some useful hints on how to go about that.

Yes, I know it's difficult to discuss a hearing loss and its impact candidly, and sometimes publicly. But it may save your job — as well as your self-respect.

I recall a conversation with Senator Bob Dole in early 1988. I suggested that the Senator should reveal himself more to the public; that he should share his feelings resulting from his grievous war injuries and describe his life experience of operation after operation — I said that people would relate to such experiences and understand him better. Senator Dole said, "Rocky, that is very hard for me to do."

I can only say to you what I said to Senator Dole, "It's hard for all of us, but at some point in each of our lives, we have got to do it." He did — and so can you.



# 1989

“With the encouragement I gleaned from what was written in the *SHHH Journals*, I did not withdraw from the hearing world, I went forward to learn. Your 14 years with SHHH helped me to surmount my own hearing loss.”

**George Kauffman, Philadelphia, Pennsylvania**

*January/February 1989*

## **Using Technology**

With all the marvelous advances in technology, I have come to one conclusion with reference to the hearing health field. Technology, no matter how advanced or seemingly magical, can only contribute what the user permits. This conclusion is based on observation of our members’ attitudes toward and experience with technology related to hearing impairment.

Stated another way, the human being is the key factor in situations involving technology. John Naisbitt (*Megatrends*, 1984) talked about “high tech/high touch” — meaning that every technical device, to be successfully marketed and used, had to have a corresponding human acceptance. This is certainly true in the hearing health field.

In this issue, you will find a poignant conversation between Pat Clickener (former SHHH president) and the SHHH national office staff. Pat has just had her “hook-up” after cochlear implant surgery and she is describing her experiences.

Technology is often evolutionary rather than revolutionary and so it has been with movement from one-channel devices to multi-channel devices (one of which Pat has). As better ways are found to stimulate the nerve of hearing with electrical impulses, users may detect a wider and more explicit range of sounds.

In the area of assistive devices, there are many things which can make the lives of hearing impaired persons simpler and more rewarding. And yet, we are slow to ask for them and slow to use them; thus bringing into question whether or not they are needed.

While the burden of matching “high tech” with “high touch” is on the manufacturers and distributors of technology, we could help ourselves by being more open to its use and by, at least, trying out such products whenever we have an opportunity.

Take a leaf from Pat Clickener’s page — “Go for it!”



*March/April 1989*

## **Keeping Channels of Communication Open**

As we move toward our tenth anniversary celebration, I have begun a review of what went on during those years. Some of my early writing for SHHH seems pertinent today:

- Regarding our accomplishments: “A drop of hope has become a flood of help resulting in widespread happiness. No picture, however beautiful, can compare with people helping people. That is SHHH.”
- Regarding self help: “We have made a choice — a conscious endeavor. Listen to Thoreau: ‘I know of no more encouraging fact than the unquestionable ability of man to elevate his life by a conscious endeavor.’ We are becoming, becoming and becoming.”
- And then: “People need people. We need each other. A friend is a person whom one is in need of and by whom one is needed. We need to know we are wanted, trusted and loved. We need people pulling for us, depending on us and expecting much of us. And we must give it all back.”

Perhaps the natural progress of personality requires first a declaration of independence and then a recognition of interdependence. So when I talk of “self help,” I mean that I have made a decision to help myself grow — to develop my potential to the fullest — so that I can interact with other human beings from a base of security and love.

Most of us recognize that human understanding is possible only as long as channels of communication are kept open. Unless we can communicate with our neighbor, we have little chance of understanding him, or vice versa. When there is a breakdown in the communications process, such as loss of hearing in one of the participants, not only goodwill but knowledge becomes important. We have to find new ways to communicate. We have to do this while retaining confidence that the human spirit is stronger than anything that can happen to it. We have only lost our hearing — not our humanness.

Once we get this in perspective we can generate the courage it takes to go on. And we go on with others. We are engaged in “self help.” We are pulling together — all crew, no passengers. And though the race be difficult, we feel better already.

Thousands of hard of hearing people throughout the United States, Canada, and Australia, have made a decision about themselves. They are learning, growing, asserting — they are Self Help in Action, ten years of it and counting.

Take a bow all you SHHHers, you have made and will continue to make a difference.



*May/June 1989*

## **Tenth Anniversary: Our Search for Liberty**

Time is short. The celebration is about to begin. Celebrating a tenth anniversary is a significant milestone in an organization's history. Doing it in the nation's capital, over a Fourth of July holiday is uniquely fitting for SHHH. It combines historic events and sites, with a methodology the framers of our Constitution would have appreciated.

As Michael Novak describes it, their main aim was liberation — political, economic, moral, cultural and religious liberation. They spoke of an “ordered liberty,” one comprising self-control and self-mastery based on virtue. It is not easy for us to master our passions, our prejudices and ignorance, so as to be able to live as free human beings. A famous student of Americans and their politics, Alexis de Tocqueville, used to say that liberty is a long schooling in virtue. The men who wrote our Constitution wanted to build a system of incentives for creative, society-building actions, and of checks and balances against negative, selfish and socially destructive actions. It was to be a system for citizens “not yet born free, not yet masters of themselves, not yet persons of virtue — but striving to become so, in order to become free men and women.” More than 200 years later, SHHH is part of that effort.

For many of us, loss of hearing has made us focus on some of the larger issues of life. In our trauma of hearing loss, SHHH has helped us learn to confront our human weakness and, perhaps, to understand, more deeply, that the main story of the human race is the story of liberty — for *all* of us. Just as hearing loss plunged us into fear, anger and sometimes, desperation, SHHH has helped us develop perspective, restored our self-esteem and once more set us on the road to liberation — freedom from all the negative influences pressing in on our human weakness. We are learning to live and work cooperatively with people of different social, economic and political backgrounds; of different ages; levels of sophistication and education; of vastly different experiences — because our commonality of hearing loss makes us structure our lives differently and in greater harmony with one another. In our chapters and groups as well as in our casual encounters, we are helping develop that socially creative and inventive society of which our forefathers dreamed. Slowly, we are becoming free.

In the Buddhist *Dhammapada*, these lines are written: “If one man conquers in a battle a thousand times a thousand men, and if another conquers himself, he is the greatest of conquerors. One's own self conquered is better than all other people conquered.”

Our successful adjustment to our hearing loss is a broad, ongoing, learning process. That process can help us reach the liberty — the freedom we all seek. At our tenth anniversary SHHH Convention, we will celebrate that process. We will celebrate it in our nation's capital with the knowledge that SHHH reflects the philosophy of our Constitution and the people for whom it was designed.

Come see and taste the wonderful goodness of people celebrating freedom. Happy tenth anniversary, SHHHers, and happy Fourth of July!



*July/August 1989*

**Making Use of Non-Verbal Communication**

A hearing friend of mine once asked me how I could possibly understand the nuances of speech, how I could grasp the meaning of the message conveyed, if I couldn't hear his words. At the time, we were in an intimate conversation which involved a great deal of feeling and he wanted to make certain that misunderstanding did not cloud the issue further.

The question was made to order for an old speechreader who also knew something about non-verbal communication. I recalled that *Psychology Today* had published an article many years ago by Albert Mehrabian. The author's thesis (based on research) was that feelings are communicated less by words than by non-verbal means. He even had a formula for it:

“Total Impact = .07 verbal + .38 vocal + .55 facial.”

Many of us would scoff at scientific intrusions into the “art” of communication, but measurements aside, a great many forms of nonverbal behavior can communicate feelings: touching, facial expression, tone of voice, spatial distance from the speaker, posture, rate of speech, errors in speech, etc. When vocal information contradicts verbal, vocal wins. If someone calls you “sweetheart” or “baby” in a nasty tone of voice, you are likely to feel disliked. That's why my hearing aid, which gives me vocal information (i.e., intonation, stress, length of frequency of pauses, etc.), is very important. This kind of information is lost when speech must be written down.

Facial expression, touching, gestures, self-manipulation (such as scratching), changes in body position, and head movements — all express a person's positive and negative attitudes, both at the moment and in general. Many reflect status relationships as well. Movements of the limbs and head, for example, not only indicate one's attitude toward a specific set of circumstances but relate to how dominant, and how anxious, one generally tends to be in social situations. Gross changes in body position, such as shifting in the chair, may show negative feelings toward the person one is talking to. They may also be cues: “It's your turn to talk,” or “I'm about to get out of here, so finish what you're saying.”

As persons with hearing impairments, we are generally more attuned to non-verbal language than hearing people. And yet, it's surprising the things we can learn. Visit your local library and check out a few books on this subject (include body language as a subject heading). You will find it fascinating.



*September/October 1989*

## **Facing Our Fears: The Bethesda Experience**

“Fear not,” we were told from a very early time. Literature, through the ages, from the Bible on, has noticed the human tendency to be fearful. Orson Welles' “War of the Worlds” aired on October 30, 1938. It was a vivid description of an imaginary invasion of Earth by Mars. Though clearly described as fiction, it threw the nation into a state of panic. Fright beyond belief! Not even the trauma of the Japanese invasion, three years

later, exceeded the Welles scare. But Franklin Roosevelt, cognizant of the fear generated by the Welles radio broadcast, took to the airwaves himself to tell the nation, "The only thing we have to fear, is fear itself." He was right.

Fear develops when we feel threatened. Its consequences are varied, complicated and often contradictory. It can immobilize you when you want to move and drive you when you want to pause. But mostly, it leaves us in a state of anxiety.

In reviewing evaluations of our Tenth Anniversary Celebration (our fourth convention), there was one thing that everyone agreed to. The question asked was what did you like best about the SHHH Convention? Practically every respondent cited the "friendly people." The conventioners helped each other, worked and played together and created a relaxed atmosphere which reduced anxiety. We literally had fear on the run. It was nowhere to be seen. One woman wrote: "How can I go back to my world of fear and anxiety after experiencing five days of love and peace?"

We urge you to join an SHHH chapter whenever possible. There you will enjoy a similar experience of caring, friendly and empathetic people. Many of us are particularly frightened by being alone, by not understanding our limiting condition, by lack of adjustment to the new reality of hearing loss in our lives, or by other self-imposed feelings which can be alleviated by association with SHHH members. Self help is rapidly becoming the primary treatment of choice for any number of personal problems. Try it, and come to Convention 1990 in Little Rock, Arkansas, for the education and professional input we need while taking responsibility for our lives.



*November/December 1989*

## **Re-Dedicating Ourselves after Ten Years of Progress**

We celebrated "A Decade of Legislative Progress" for hearing impaired people at our recent convention. Obviously, there is much more to celebrate. As our tenth birthday approaches (November 27, 1989), we refer again to our roots — the self help philosophy. Our successes are many but the most cherished are those which have, in some direct way, improved the human being. We have stimulated in our members the determination to live their lives to the fullest extent possible, despite the handicap imposed by hearing loss.

My friend, Dykes Cordell, M.D. puts it beautifully:

"This determination to participate is not the routine response of adults who experience a loss of hearing, nor was it the initial response of the majority of SHHH members to their own hearing loss. The 'identification' process and the personal support exchanged among group members facing similar problems has resulted in changes in the individual which have opened what previously seemed to be closed doors of opportunity. This has been accomplished independently of any dramatic shift in the actual societal and vocational opportunities available to hearing impaired people.

*"The key to SHHH's success has been its ability to awaken dormant powers within the individual to allow maximum use of available options.* The results in terms of improving the human condition, certainly for SHHH members and, in the long run, for thousands of other hard of hearing people, have been more immediate and pertinent than

could be expected from attempts to change institutions and the general awareness upon which institutions are based.”

Conventional wisdom says it takes ten years to establish a national organization. We are well-established in that regard, but our success has made us even more aware of how much needs to be done. The enormity of hearing loss and its consequences are just beginning to seep into the national consciousness. We have much to do.

In November, as we celebrate Founder’s Day, we have every right to be pleased with our first decade of progress. But that also will be an occasion for us to rededicate our energy and talent to helping others to learn and share our experience; to make a commitment to participate in making hearing loss an issue of national concern; and to reflect on SHHH as an organization with the realization that without your national office, none of the things we celebrate now and want to do in the future, would be possible.



# 1990

“Whenever I see Rocky, my spirit is rekindled and my batteries recharged.”

**Nettie Allen, Columbia, South Carolina**

*January/February 1990*

## **Your Expanded SHHH Family**

Families have normally been the core support structure for people. Certainly there are exceptions, but basically, we hang together. In spite of differences, complex relationships, inherent tension and external pressures, the bottom line is love for one another, and help to family members in need at any given time.

In the best sense, parents learn how to provide for their children’s needs as they grow; how to empower them to become individuals while teaching them that we are all interdependent; how to assure them that while we may not always agree with what they do, they can do nothing to deprive themselves of our love. As siblings we learn how to give and take; to experience sharing and cooperation — the beginning of a lifelong negotiation process. And in today’s world, children are finding themselves increasingly in care-giving roles to parents as our population ages.

What makes SHHH so remarkable, at least to me, is that thousands of people who have never known one another can move the concept of family into such broad dimensions. I have told individuals whose self-esteem was at rock bottom and who were in the death grip of acute depression, that if they could just attend our next convention, their lives would be changed. Some did attend and their lives were changed!

Your acceptance of persons as they are reminds me of our “Old West.” There, when a person rode into town, no questions were asked. The new person was simply accepted. True, circumstances could change that acceptance but the opportunity was there to go forward into the future without scrutiny of the past.

SHHH members have that characteristic. Given the opportunity, many of us will see new reasons for trying harder, for really living again rather than being resigned to the negative aspect of our situation. Acceptance is a beginning.

Expanded family. That’s us. We really are learning that wonderful lesson — love one another!



*March/April 1990*

## **The Impact of SHHH Conventions: Little Rock**

Having annual conventions takes a lot of doing. Most good things do. We believe that by moving convention sites around the country every year, more of you will have an

opportunity to experience something which has proven to be truly wonderful. So much so, that we are seeing a growing group of persons who attend every convention. Although there is, necessarily, some repetition in content, each convention is significantly different.

So much is happening in the hearing health field and in the movement toward more complete communication access for hearing impaired persons, that it is difficult to keep current — even with annual conventions. New and improved hearing instruments and devices come on-stream regularly. Research into hearing loss and its complications is picking up. Important legislation is in the mill at both federal and state levels. Most important of all, hearing impaired persons themselves are increasingly participating in solutions to their own problems.

A convention, with its opportunities for hands-on experience in the exhibits hall and for in-depth knowledge on a variety of subjects through workshop presentations, is the best existing means of keeping up with developments in our field. In fact, participation in a convention is so important that every chapter and group of SHHH should attempt to have someone present who can take everything he or she learns and pass it on to others at home. Information gained in a convention experience helps build a solid base for networking. Exchanges of views from a common database will lead to more knowledge, more participation, in an upward spiral.

This year, in Little Rock, Arkansas, we will have much greater emphasis on vocational rehabilitation and the value to you of relationships being developed by SHHH with other organizations. Trends in research (some of which involve SHHH), and reports from major research centers will be discussed. Progress reports on the implications of the far-reaching *Americans with Disabilities Act (ADA)* will be available, and specific plans for achieving communication access using the *ADA* as a springboard for actions will be discussed.

Progress in all of these areas is directly related to the degree of interest and participation. Come to Little Rock as a manifestation of that interest and help us move more rapidly toward making hearing loss an issue of national concern.



*May/June 1990*

## **Noise-Induced Hearing Loss**

We are a strange people! We are concerned about the carcinogenic qualities of what we eat. We worry about our cholesterol levels. We ban smoking in airplanes, lest we inhale smoke which might make us ill. If our roof contains asbestos, it's cause for alarm. We drink bottled water for fear of impure elements in tap water and then find that bottled water is not clean either.

Yes, we worry about all these things and more. But noise? Do we worry about noise? Do we worry about losing our hearing as a result of noise? "Nah, it's part of the scene, man!"

Indeed, it is part of the scene. We are immersed in sound. But when does sound become noise? And how does noise affect our physical and emotional well-being? Noise

is unwanted sound. It is sound which has an adverse impact on us. It can make us angry or just irritable; listless or unable to sleep. And it puts us at risk in terms of our hearing.

Noise-induced hearing loss is the single greatest cause of hearing impairments today. And it is permanent! It won't go away. As yet, there is nothing we can do to make it go away. But we can do something to reduce the risk of noise. We can work toward prevention and toward the reduction of environmental noise.

Such activity involves choice. Many of us accept dangerous noise levels for convenience (for example, air conditioners, power tools, hair dryers, airplanes, etc.); some of us choose dangerous sound levels for pleasure (for example, rock or concert music at high volume via headphones); and others of us simply tolerate noise as a condition of employment. To exercise choice intelligently, we need accurate information.

The first thing we must understand is that hearing loss occurs at noise levels which many people believe are harmless. Certainly, the ear, as part of that marvelous human system we call body, has built-in protection. Special muscles can tighten the eardrum against the surge of too much sound. Other muscles can pull the stapes out of the oval window so that it doesn't transmit damaging levels of vibration to the delicate structures of the inner ear. But any emergency system only safeguards a mechanism from the perils it was designed to protect against. The human ear cannot protect itself against high-pitched and long-lasting sounds. Nature won't save us. We must help ourselves.

In this issue we explore some of the problems of noise in our environment — and what we can do about it. Make no mistake, the stakes are high. And we who sleep in continual noise may awaken to silence.



*July/August 1990*

## **Recognizing Options for Rehabilitation**

I have been engaged recently, in the preparation of various grant proposals. Such activity is exciting for me because I'm forced to slow my action mode and spend more time reading and thinking. As I worked on the review of the literature section for one proposal, I was struck by how most scientific attention to hearing impairment has been focused on its interference with communication. You and I know that hearing loss disturbs more than communication. Perhaps that is one reason why many rehabilitation programs have not been very successful in leading to good adjustment by persons who lose their hearing as adults.

In my view, objective and subjective factors must be considered. The intellectual and emotional components of hearing loss, as it affects the individual, need close examination. When we lose our hearing, we have a limiting physical condition. What makes it a social, psychological problem, is our inability or refusal to compensate by obtaining information in other ways. Ignorance plays a role here, since many persons are simply unaware that there are options available for effective action. Our task, as Ron Whyte once phrased it, is "perception: discovery, definition, action."

An important function of human beings is to understand ourselves and those with whom we come into frequent contact, all in the context of our own strengths and

limitations. We need information — options available to us in different situations — to really give ourselves a fair chance. Reading this journal helps. Greater help comes from being part of an SHHH chapter where you have the experience of interacting with all different types of persons who share at least one thing: hearing loss.

Shared experience in the self help methodology ensures inclusion of social, psychological considerations of the impact of hearing loss on the person. It acts as a supplement to services and information provided by hearing health professionals. It brings some of the abstracts mentioned above, to life. Shared experience is an extension of the rehabilitation process and augments professional care.

Many of us are deeply into this type of extended rehabilitation and many of us are already well-adjusted to our circumstances of life with hearing loss. We have discovered what has actually happened to us (as opposed to worrying about things we think are happening to us); we have defined the problem and our relationship to it; and we are taking action to adjust to new circumstances in our lives based on solid information. Quite an accomplishment!



*September/October 1990*

## **Evolving into the Future**

We are changing. Not in the sense of becoming different, but more in the sense of passing gradually into a new form — as summer changes to autumn. This *Journal* has evolved over the ten years of its existence. We think it has gotten better. We want to continue to improve it: to give you increasingly better quality of content; to make it more easily readable; to groom it and make it more attractive. As always, it's important for us to grow together, so let us know what you think of our new look.

This attempt at continued improvement in the *SHHH Journal* is a symbol of our work with you. It is an integral part of changing ourselves, our lives, for the better — through consistent, determined effort. Never have hard of hearing people been in a better position to do so. We have resources: increased awareness of self; increased awareness of each other; and the mechanism of SHHH always ready to help. We have leverage: increased public awareness of us as people; the law (*The Americans with Disabilities Act*); and improved relationships with our professional associates. What is needed now is commitment — a resolve to use together, what we have worked for, and what others have come to provide.

Each one of us has to make his or her own commitment. Will we recognize the advantages we now possess? Will each of us realize that it's better not to "go it alone?" Will we see the considerable progress of the last ten years and recognize it as a process in which each of us can participate, and thus benefit? Will we see change as modification and adaptation, rather than rupture? These are a few of the questions which, if answered in positive fashion, can lead to commitment. Whatever our choice, it will set the tone for the future. It's up to us.



*November/December 1990*

## **The ADA...A Challenge to You**

Civil rights are the treasured heritage of all Americans, safeguarded by the Constitution and the Bill of Rights. That's the *principle* involved. Clearly, there is a gap between principle and reality. I find many things communicatively inaccessible — to me, as well as to millions of people like me. Implicit in the existence of barriers is the denial of fundamental rights: the right to assembly, the right to employment — even the right to due process, because many courtrooms are among public facilities that remain communicatively inaccessible.

Certainly, denial of access, be it physical or communications, is in violation of both the spirit and the intent of civil rights laws, particularly as they have evolved through clarifying legislation and court tests over the last 20 years. The law represents a major resource — and sometimes the court of last resort — to which handicapped people — must turn if their rights are to be affirmed.

Bingo! Did you hear that word “affirmed?” Now we are getting to the practical aspects of access. *We* — hearing impaired people — must do the affirming. Our record in this regard is weak.

Since 1973, the Congress has sought to forbid discrimination against all handicapped individuals. On July 26, 1990, President Bush signed the crowning achievement of this long Congressional effort — the *Americans with Disabilities Act of 1990 (ADA)*.

The law is a tool which we must be prepared to use in asserting our rights within its framework. Without our action, this landmark legislation will be of little value to people who are hearing impaired

Interpreting and implementing existing legislation and regulations become increasingly difficult as we move away from a clearly defined, far-end-of-the-spectrum need represented by profound deafness — to a more complicated appraisal of functional disability affecting partially deafened persons with moderate to severe hearing impairments.

For example, a person with a severe hearing loss who has found successful coping strategies and who has good, supportive family and friends may function better than a person with a moderate loss who finds the situation devastating.

Government, academia and industry are beginning to recognize the problems of partially deafened persons and are demonstrating a willingness to provide services to and make accommodation for this large population. But it's slow going.

This issue of the *SHHH Journal* is dedicated to making you aware of and willing to do something about the opportunities provided by the *ADA*. *You* can speed up the pace of change. *You*, each one of you, can make a difference!

# 1991

“Rocky provided each of us with a toolbox to fix that breakdown in communication. He gave us the desire to teach others to use those tools, to help them find the switch that turns on the light to remove darkness from hearing loss.”

**Ernie Fuller, Las Vegas, Nevada**

*January/February 1991*

## **Family Communication... an Act of Love**

Publications are developed over a continuum of time; this one included. That is why I'm writing this in November for you to read in January or February. As it turns out, our theme for this issue is family. Thanksgiving Day has just passed with all the nuances of family that we attach to that uniquely American holiday. A nice match.

My experience of holidays which involve the gathering of the clan (15 to 20 depending on the holiday) is mixed. The noise, the confusion, children's incomprehensible voices, all constitute a problem for hard of hearing persons (and sometimes for hearing folks, too). But, for me, what has become the most consistent centerpiece of these gatherings is the effort everyone makes to facilitate my understanding of the conversation: “Michael, look at Rocky when you speak to him,” Jolie tells her three-year-old son. David, the nine-year-old son of Melanie, walks up to me and looks me in the eye as he communicates his news. Even Ted, her younger son tries (when he remembers) to “help granddaddy hear.”

At the dinner table, family members take turns, in a very natural way, keeping me posted: “Rocky, we are talking about...”; “Dad, we are discussing...” And, so it goes throughout the meal. I have said this before but it bears repeating. The effort being made on my behalf goes far beyond the courtesy of keeping me involved. It is an act of love. The love that holds families together. The love that sharpens awareness of another family member's needs; that deepens commitment to one another (thoughtful and interactive); that provides mutual support by acceptance; and that generates a healthy environment of potential growth for all members of the family.

Stories of struggle within families abound. Our fights with each other; the trauma of parent/child struggles as the child seeks independence; etc. Transcending all those incidents is love. That is why when one feels rejected — for whatever reason — it is a serious problem. Rejection is often perceived as a loss of love rather than just one more transitory incident in family life. Family is, for most of us, the primary support structure. The loss of that source of support affects us in many different ways that remain with us for long periods of time.

When we are fortunate enough to have a loving family, willing to assist us through difficult times such as those experienced by persons who lose their hearing, we must never forget the reciprocal aspect of love. We used to sing about it. “The greatest thing you'll ever learn is just to love and be loved in return.”



*March/April 1991*

## **A Prayer for Those in the Gulf War**

The adjustments we make in our daily lives are most often caused by necessity, but sometimes they occur in the interests of perspective. So it was that just as I started to write one more item on hearing loss, the United States went to war. My mental gears shifted from the trials and the tribulations of those experiencing loss of hearing, to the thousands of human beings on both sides of this conflict who will lose their lives. This mental shift brought perspective to such issues as pain and suffering, and how we struggle to hold on to life even in the most difficult circumstances. It put, for the moment, our personal problems on the back burner.

However controversial the issue, it is evident that many of us recognize the transient nature of life and that there are some things for which we must sacrifice it. In the process, it is usually the innocent who make the sacrifice. As the philosophy translates into reality, and decisions made by some result in the death of others, we sense a loss of control over our personal lives. Depending on circumstances, we may have had little or no control to begin with, but the dramatic imminency of war and its consequences enhances that sense of loss.

It causes a pause, an historic comma, in the development of the self help concept which teaches each of us to take responsibility for our life. It puts pressure on us to subordinate our individuality to the perceived greater good for the community—in this case the international community. It causes us to think in broader terms and to try to determine how we fit into the complex and often contradictory patterns of life on planet Earth. The sharpness of our thoughts may be determined by how close we or our loved ones are to the razor's edge of conflict, but the poignancy of the moment affects us all. We are engaged.

I pray that by the time you read this, the worst will be over, as unlikely as that seems. If not, as we move through life in pursuit of our own concerns and attempt to cope with our own problems, let us keep in our minds, our hearts and our prayers, all those more directly involved in the war. Let us recognize that our problems, no matter how great they seem on any given day, pale in comparison to the problems of life and death now being encountered by so many of our sisters and brothers. Meanwhile, let us enlarge our immediate areas with the spirit of love and respect for all human beings as a continuation of our self help philosophy.



*May/June 1991*

## **Regaining Control after Hearing Loss**

Even reasonably secure people seem to develop insecurity as a result of the onset of hearing loss. Somehow, our world seems changed. We find ourselves standing on the shifting sands of doubt — lower levels of self-respect and frequent bouts with depression. Is this inevitable? Absolutely not! T.S. Eliot described permanency as having the components of love, loyalty, faith and friendship. Hearing loss *can* impact adversely on all four areas and thus cause unwanted change. But, “it ain’t necessarily so.”

The way out is knowledge of what has happened to us. We have simply lost some or all of our hearing. We have not lost our values; our capabilities (although we will need to do some things differently); our capacity for love, loyalty, faith and friendship. We have not lost our insight or our ability to think, reason, and ultimately find our way to a somewhat different reality of life in the tactical sense. We remain unique human beings — worthy because we *are*.

The big obstacle seems to be that in our frustration, and often depression, we have a diminished sense of discipline. We kind of fall apart for a while. It takes determination and discipline to pull ourselves together again. Sometimes we can’t do it alone. That’s why the logical extension of self help is mutual help. Not everyone is capable of handling problems alone.

The ringing words in our Declaration of Independence mean we are all born equal, in terms of our humanness, but not in terms of our capability, so we strive for equal opportunity in our society to help bridge the gaps. And we help one another. We try to love people and use things, rather than loving things and using people. We try to avoid the pitfalls of changing the Ten Commandments into the ten suggestions. We need, and try to develop, discipline in our lives, based on respect for one another. That’s how self help expands into mutual help.

Secure people feel good about themselves. If you are fortunate to be able to attend the SHHH Convention in Denver, you will meet a lot of people who have re-learned how to feel good about themselves. They will help you find your way if you need help. Come to the party! It’s a celebration of life!



*July/August 1991*

## **Compassion and Forgiveness...Keep Trying**

I was talking to Laurel Glass the other day. Laurel is both an M.D. and a Ph.D. More importantly, she is a superb human being. She was describing how much she is enjoying her current research involving many, many members of SHHH. She said she was learning a great deal from and about hard of hearing persons. She is one of us, having lost some of her hearing a few years ago.

Laurel knows, almost intimately, Deaf culture. She appreciates it, and much of her life experience has been associated with deafness. She is a member of the Gallaudet University Board of Trustees. Now that she is experiencing hearing loss, her knowledge of that condition enhances her ability to research it.

We talked about EMPOWERMENT of people, a subject in which we are both very interested. Because she is always stimulating, I continued, in my mind, to explore the implications of our conversation long after she left. She listens carefully and I reflected on how the overall impact on a person who is really listened to, *is an increase in self-esteem*. Someone affirms that I (you and me) am worth listening to!

She is very compassionate and I reflected how compassion and forgiveness are such important components of a happy home. You have heard me say before — to love is to risk. In a family, communication, compassion and forgiveness can be summed up in one phrase (according to William J. O'Malley): “vulnerability to one another.”

The vulnerability referred to requires an understanding that although “we may accept the invitation to grow beyond our animal origins, we never leave our animal nature behind.” Yet we need to go further — compassion is impossible without the self-esteem that allows one to be vulnerable. We must be secure enough to know how weak we are. How can we “walk a mile in someone else’s shoes,” if we are bottled up in fear? That’s where “the truth will make you free” comes from. Knowledge of the hard reality of life is more useful to young people than overprotection and the illusion of false security. This is something parents often miss.

In short, we are a wonderful, but imperfect, people. We need to trust each other to have any confidence in ourselves. We need to love each other (which means to accept vulnerability); we need to forgive when our trust is misplaced simply because we are all imperfect. Self help not only means assuming responsibility to ourselves, but an awareness of what humanness means, and an acceptance of each person wherever they may be at any given time. Keep trying.



*September/October 1991*

## **Moving Toward a Better Life**

As the scorching heat of summer begins to recede, we anticipate the beauty of fall unfolding in a blaze of diverse colors.

It’s an expectation we can count on.

Nature lends itself in providing stability to our otherwise changing lives. Perhaps, pace is the provision making this aura of stability work. Movement is slow but steady.

There’s an apparent regularity — this we know holds true as the news is filled with reports of major natural destructions — occurring as nature turns violent and destructive.

Life is filled with contradictions. Those who attended the 6th Annual SHHH International Convention in Denver, Colorado, were able to witness life after hearing loss demonstrated in all dimensions. Many were made aware of the contradiction between the public image of persons with hearing loss and the self-image of our 1,100 convention-goers.

The professionals we met during the convention were amazed by our exuberant joy of being in each other's company.

The ambient reflection of the self help movement was evident.

The hunger for information sought to help in coping with hearing loss and the willingness to give technology a chance were self-evident.

Although our confidence in these things can't match knowing that the sun will rise tomorrow — it, too, is a change. We are moving slowly in the direction of a better life. If, like nature, we continue to evolve, to stay relevant to the world we live in — then we can better integrate our hearing loss into the appropriate lifestyle.

Life's stresses will soon diminish. And then we can relax and enjoy the beauty of fall as it was meant to be. Try it.



*November/December 1991*

## **Meniere's Disease**

It has been estimated that there are 545,000 individuals in the United States with Meniere's Disease. Approximately 38,250 new cases are diagnosed each year. Those numbers make Meniere's a fairly common clinical experience. Yet the cause and pathology of this frustrating ailment continue to be elusive. With all the wonderful advances in medical science, Meniere's is one of the conditions which remain unresolved.

The National Institute on Deafness and Other Communication Disorders (NIDCD) and the National Institute of General Medical Sciences are involved in research, which, hopefully, will contribute to a better understanding of and treatment for Meniere's.

NIDCD would like to see a careful search for the presence of actual viral agents in the inner ear tissues of patients with Meniere's. Also, studies of the hyper-responsiveness of many Meniere's patients to specific viruses need to be validated, further defined and related to the inability of these patients to return to normal auditory and vestibular function. The possible role of the time course of childhood viral ear disease in later Meniere's Disease needs further work.

NIDCD would like to budget some \$3.5 million over the next five years on these subjects, as well as a little over \$4 million on the autoimmune and allergic bases of Meniere's. The National Institute of Allergy and Infectious Diseases also will be conducting research in these areas.

For older persons with Meniere's, this may not hold much hope, but work is continuing in a search for means to alleviate Meniere's. I am confident that such efforts will bear fruit in the not too distant future.

Meanwhile, we will keep reminding NIDCD of the importance Meniere's research.



# 1992

“The same doors Rocky Stone opened for me, he has opened for thousands of others too. The example he has set, his passionate love of the human spirit, and mostly his belief in others, has motivated and left an indelible mark on all those whose lives he touches.”

**Joan Kleinrock, Bethesda, Maryland**

*January/February 1992*

## ***SHHH Journal* Receives Gold Circle Award**

News of the Gold Circle Award being given to SHHH by the American Society of Association Executives (ASAE) for the “most improved journal/magazine” should bring joy to all of you, but come as no surprise.

The *SHHH Journal* has evolved steadily into a top-flight publication. The drive toward excellence has been a function of Barbara Harris, our editor. You who read the *Journal*, who give us feedback and who often contribute to its content, also share in this award. Jeffrey Hughes, who, as previous editor and current graphic designer, has also played an important role in the evolution of the *SHHH Journal*.

The Gold Circle Award for Excellence in Communications is given, specifically, for development and improvements in the past year. Those improvements resulted from a conscious decision to redesign the *SHHH Journal*, to improve its image and content, to make it easier to read, and, in general, to better serve our membership. Barbara handled this project with determination and skill and the result was national recognition for us all.

We at SHHH are not professional people but people who perform professionally. In typical self help fashion we identify what needs to be done and then set about doing it in an effective manner. Your national staff has grown in number as well as in competence as we attempt to serve the many requests made of us.

SHHH has become a national resource, a clearinghouse of information on hearing loss, providing reliable information. It’s a resource of which you, who support it, can be proud.

We have seldom wasted time “tooting our own horn.” But when something like the Gold Circle Award comes your way, it’s time to take stock and be thankful for what you have built.

Thank you for all your support — then — now — and in the future. You are all, as we say in Washington, “in the loop.”



*March/April 1992*

## **When You Have Both Hearing and Vision Loss**

I had an eye examination today. Very thorough. One hour and ten minutes.

I have a degenerative disease associated with aging. It's located behind the eyes. I can neither see it nor pronounce it. But it's there. Lurking. A threat. Why a threat? After all, it happens to millions of people. Obviously, a word of explanation is in order.

Those of you who know me well, know: that I am blind in my right eye; that I get most of what I understand of speech through the use of my left eye (speechreading); that even partial loss of that left eye will put me in the unenviable category of persons who are deaf and blind — and I'm no Helen Keller! But the threat is real — and it's something I, like many of you, must face.

In view of the fact that I'll be leaving SHHH soon, perhaps working with deaf/blind persons could be a third career for me. Whatever the future holds, the news makes me think — and plan. How would I handle such circumstances? Trying to prepare for such an eventuality does not mean you expect it. No need for self-fulfilling prophecies here. Preparing *does* give you a jump on the situation, *should* it occur. Analyzing the situation and projecting a worst-case scenario — *without fear* — is a good way to start preparation.

Some time ago I gave the Helen Keller National Center my word that SHHH would pay more attention to people who have low vision and low hearing. You may have noticed our frequent references to a large-print *SHHH Journal* and our current offer to those of you who need large print. SHHH has supported and participated in the first National Conference for Vision and Hearing Loss Among Older Adults coordinated by the Helen Keller National Center. A second one is planned for November 1992, in Dallas. We'll be there.

This issue of the *SHHH Journal* focuses on low vision/low hearing — a condition which increasing numbers of older people face. We want to help prepare you — not scare you — for eventually having to do something about that condition.

In my case, I'll contact a retina specialist and determine the extent of my disease and then decide whether I need surgery now or to just keep careful watch on the condition. No panic.

I'll also investigate the many assistive devices that enable persons with low vision to continue reading. Even if I lose my ability to speechread, the fact that since age 19 I've gotten the greater part of my information (what I know) from print material, should encourage me. Being able to see well enough to speechread and being able to read print with assistive devices are two very different things.

Can we help develop better hearing aids to enhance the ability to understand for people with hearing loss who also have low vision? Can we work on captioning to enhance the ability of persons with low vision to see and understand captions? Can we bring the National Eye Institute and the National Institute on Deafness and Other Communication Disorders together to jointly study and alleviate these problems? There are many things we can do.

Let's plan together, and those of us who may experience this condition will be better able to cope with it because of our foresightedness (no pun intended).

Think about it — and share your thoughts or experiences with SHHH.



*May/June 1992*

## **Where are You on the Scale of Happiness?**

Spring is in full bloom. Presidential campaigns are in full swing. The economy is looking better and school is almost out. Those are things happening in our environment, but many are asking the important questions, “Where am I on the scale of happiness? What am I doing with my life?” If you are among those seeking such answers, you are fortunate. Many sick, poor, hungry, and homeless persons cannot even think on that level. They are simply trying to survive.

Whatever pain hearing loss causes an individual, being a member of SHHH brings increased hope. Without hope, little is left with which to answer the questions above. Happiness is reached through a combination of circumstance, and physical and mental attributes. (Believe it or not, money won't do it.) SHHH helps by giving you options, by showing how you can improve your life with a hearing loss, and, very importantly, by bringing you into contact with role models and others with hearing loss.

I am very much aware that only a portion of our membership belong to chapters or groups. That is why we move our conventions around the country every year — to give those not in frequent contact with others with hearing loss that opportunity. I feel so strongly about personal relationships that I would like those of you who cannot (for whatever reason) join an SHHH chapter or group, or attend a convention, to write to us at SHHH National so we can perhaps arrange one or more persons to visit with you. People need people and although we may not have a chapter near you, we may well have members in your area who would be happy to visit. Observers over the years have noted that what we do for ourselves dies with us, but what we do for others remains and perhaps grows, as example inspires imagination. Everyone wins. The giver and the recipient.

From June 25 through June 29, some 1,000 members and friends of SHHH will meet in Cedar Rapids, Iowa — a city of warmth, filled with friendly people who will be our hosts. This combination of REAL people promises to create an atmosphere we will cherish long after the event. Try to come. You, like thousands before you, will find yourselves feeling uplifted — more knowledgeable, more determined, and more accepted and comfortable with yourself and others who, like you, have a hearing loss.

See you in Cedar Rapids!



*July/August 1992*

## **Abusing Alcohol**

Substance abuse! A broad but deadly term. This is one more area where hard of hearing persons need effective communication access.

I cannot write with any confidence about the broad term substance abuse, but I think I have a “feel” for alcohol abuse among hard of hearing people. While “alcoholism” among hard of hearing persons may not be higher than the national average, I believe that “usage” and perhaps the existence of a “drinking problem,” is higher than the national average.

I get this impression from hundreds of visits to groups of people who are predominantly hard of hearing or deaf. I get it from the many stories that people tell me about their stressful lives and their reactions to life and its problems. I get it from my own reaction to particularly stressful days. I go home and fix myself a drink (or two, or three...).

There are different psychological, biological, physiological and other reasons for why we drink, how it affects us and why we let it become a habit and eventually a dominant in our lives. I don't know them all. I do know “social drinkers” are often “problem drinkers,” and those of us who drink when under pressure run a risk far greater than we know.

Hard of hearing folks are often known to be “depressed.” Drowning your frustrations doesn't really do away with them — it usually deepens the depression. Given enough continuity, depression can become a killer. It kills the spirit, the will, the mind and sometimes the body. It often puts us into an “I don't give a damn” frame of mind. Not healthy!

As you read this issue, be honest with yourself. Examine how much you drink. Consider, as honestly as possible, when, where and why you drink; how you react; the price you have already paid. I suspect that some hard of hearing persons try to handle such problems alone because of the hassle involved in communicating about the problem. Few can do that successfully. Most people need help. SHHH would like to make sure that help is available to hard of hearing persons when they need it.

If you decide to get help, consider this step as a major one in your life. You (and your family) will want to be sure the program you go to will provide services that are sensitive in your communication needs.



*September/October 1992*

## **We All Have Potential**

The clock is running down for this column (five more to go). Rather than blend in the feature articles in this issue, I'm going to unburden myself of some thoughts before I leave you.

How does an organization like our function in a money-driven society where we have institutionalized greed? The thinking behind my choice of the self help philosophy for SHHH was to enhance each one of us as human beings. Hearing loss was an important but secondary consideration. Once we accept responsibility for ourselves, we have to learn to love ourselves and, then, each other.

The initial stage does require looking inward. It means learning to trust yourself; to allow yourself to feel your own emotions; to take time for the release of emotional pain, for creativity and play. That turning inward should bring you to a level of feeling good about yourself from which you can reach out with confidence — to be a self-helper in mutual support. We move toward the understanding that we can never fully be valued until every other human being is fully valued. Our movement is toward a very high plane of human behavior. As self helpers, we march to the tune of a different drummer than much of society. That is why I cannot agree with some of our older people who say they have “paid their dues” and now wish only to relax. That is, of course, their choice. But they miss so much of what they could gain — and, could offer to others.

As one self helper said, “I have the right to challenge everything that oppresses me — to challenge all that holds me back from being the real me. I can figure out what could be different or better in the world to make things right for me. I can determine just where I’d like to make changes happen. Each of us is a leader. That includes me. I’ll exchange support with others who have interests similar to mine — together we can take bold and powerful action.” A very assertive woman.

We all have potential which, admittedly, is tempered by circumstances. Nevertheless, it’s there. Those of us who dedicate ourselves to being “all that we can be” enhance ourselves and usually those around us. That is what I hope for SHHH members.



*November/December 1992*

## **Reaching Out, Around the World**

A change in pace as well as in physical location can often have therapeutic effects. So it was with me. In August, I attended the Fourth Congress of the International Federation of Hard of Hearing People (IFHOH) held in Jerusalem. I gave the keynote address and two other presentations during the Congress. Representatives of national organizations of people who are hard of hearing or deaf attended.

Once more I was amazed at the reach of SHHH. Representatives from Japan, several European and African countries approached me to compliment SHHH for its impact on their activities. They receive our *SHHH Journal* and use its contents extensively. It is clear that people who are hard of hearing are awakening to their potential on a worldwide basis and that SHHH is part of their experience. It was a real thrill to see evidence of our impact.

On a more poignant note at the personal level, my wife Ahme and I had another pleasant experience. Seven years ago, we visited Jerusalem. While shopping, a man noticed my hearing aid and described his daughter (then eight years old) to us. She was a premature baby and was born with a hearing loss. He noted that she had limited services to help her and wondered if I could help. I took his name and address and enrolled his daughter in SHHH.

Seven years later, when we passed his shop, he recognized us immediately and expressed his great appreciation for the information his daughter had been receiving all those years. She is now 15 years old, struggling, but doing very well in a highly

demanding secondary school. We met Suzanne and it quickly become apparent she is a very bright young person with good potential for a professional career — if given the opportunity. Her hearing loss is interfering with that potential. Her desire at this time is to learn about hearing loss and help people with hearing loss in her community. She is interested in possibly becoming an audiologist. We are now involved in trying to help her with better hearing assistance and, through that, to give her a chance to realize her dreams.

So you see, my friends, that you have created an organization with impact on the lives of people far beyond the United States. Suzanne thanks you and so do Ahme and I.



# 1993

“At a workshop, Rocky said, ‘After all these years of being hard of hearing, I still get an occasional wrenching feeling, like a knife in my gut.’ I thought, if he feels that way, it’s okay for me to feel that way too.”

**Nancy Wessner, Pittsburgh, Pennsylvania**

*January/February 1993*

## **To SHHH’s Wonderful Membership...*You***

With the coming of a new year, things change for some of us. For me, it will be a radical change. I will be leaving SHHH. Although I will continue to be active in the hearing health field, I will not be associated with SHHH. A clean break is best for my successor, the membership and for me. I will not be on the board of trustees and I will not meddle with the National office. SHHH is not mine — it is yours.

It is yours to take to new heights; yours to reach out to the millions of persons with hearing loss who have never heard of SHHH; yours to continue educating the hearing health providers; to advocate for the rights of *all* people with hearing loss; to show persons with hearing loss how life can be beautiful — *with* hearing loss; to work together with other persons and organizations for the betterment of all persons with disabilities; to move to new and higher levels of human behavior; in short, to be the human being you want to be and can be.

Those are some of the things SHHH was set up to do. You can make our dreams come true. You have always encouraged me and enhanced me. Soon, you will have a new executive director to support, to help do the best job possible for SHHH. I’m sure you will provide excellent support.

Founding SHHH and working with you has been an exhilarating experience for me. After two years of preparation and more than 13 years nurturing SHHH, I find that the thousands of rewards I’ve received are the personal contacts I’ve had with you. From you, I have learned a great deal. You have shown me courage, imagination, sensitivity, intelligence, patience — even fun. SHHH has a wonderful membership — You!



*March/April 1993*

## **The Human Spirit First; Only Then, the Hearing Loss**

The level of political rhetoric has dropped considerably in the last few months, but maybe you remember the tug of war about family values. I am not interested in defining how families should be structured but I am concerned with how our children acquire the values they need.

I agree with David Kearns (former Deputy Secretary of Education), who said, “We are not born with values. They are taught, learned and practiced...at home, in school, on the playground and in our neighborhoods, by the way we act as adults, by the way we conduct our businesses, and by the way we treat each other.” Kearns has been stressing for years the need to educate *all* of our children and to make our businesses competitive — and the importance of ethics to both enterprises.

There are a lot of constants in our values. Truth is better than dishonesty. Fairness is better than prejudice. Without values, we lose our way in life. As Kearns says, “Yes, children will decide what values are important to them, but they need to know what values are important to *us*, and why.”

In SHHH, we not only share a disability, we share common principles, respect, responsibility, and a sense of belonging. We fit in well with Kearns’ thesis. More importantly, we safeguard our communities’ values and enhance the future of our children. SHHH is, after all, concerned first with the human spirit and only then about hearing loss.

One of my great joys with SHHH has been that we have kept our focus on people. As we grew, we had to adjust to running a business; to be more efficient; to not spend more than we received. I haven’t done very well in that last category. But the potential for working with so many persons in need has overshadowed my concern for the balanced budget. We will balance the budget but in careful ways which do not sacrifice our program responsibilities.

To me, *you* are, and always have been, my chief concern. And that is something of a value in itself.



*May/June 1993*

## **The Torch Has Been Passed...to You**

Time to say goodbye. Since I don’t like long goodbyes, I’ll keep this short.

First of all, I’m grateful. I’m still alive. I don’t have ulcers. I’ve had a marvelous experience. My faith in human nature has been reinforced time and again — by you! Yes, you have sustained me. You have given me your trust. (Perhaps the most important thing you can give a person.) You have given me love, encouragement and material support.

Only occasionally have you given me grief (smile) — and for the length of time we have been together, that is remarkable. I thank you all.

This ends the “Rocky Stone Era.” You don’t need a litany of SHHH accomplishments. Each of you know what SHHH means to you, personally. You know the difference in before and after SHHH.

Now, SHHH must move on with confidence. To me, each of our lives is like a thread woven into a tapestry of history. We are all part of a whole. Some of you, when you joined SHHH, had to regain your spirit. You lit a candle and joined a crusade. Now you are being asked to carry the torch. You have the capability for taking the torch from here to...anywhere.

And so, instead of saying goodbye, I’ll simply say, “The torch has been passed to you. Run as hard as you can.”



**Howard E. "Rocky" Stone**  
*Founder and Executive Director of SHHH*  
**Years of Service: 1979-1993**

Rocky Stone experienced a bilateral hearing loss at 19, during his World War II service with the U.S. Army. Following his military service, he graduated from the University of Southern California and completed one year in the master's program at the School of Advanced International Studies, Johns Hopkins University. He then spent 25 years in federal service with the Central Intelligence Agency, earning the Agency's highest award. In 1991, he was awarded an honorary doctorate degree from Gallaudet University where he served on the advisory board of Gallaudet Research Institute.

He has been honored with numerous other awards including the Distinguished Service Award from the American Speech-Language Hearing Association, the People-to-People Volunteer of the Year Award from the Committee on the Handicapped, the Herbert H. Lehman Award in Administration from the New York League for the Hard of Hearing, the Outstanding Achievement Disability Project Award from the American Association of Retired Persons, the Howard House Award from Sertoma International, and a recognition for his contributions to individuals with hearing loss from the American Academy of Audiology.

Since 1977, he has served as a founding member, volunteer, consultant, and elected chair of various organizations and committees, at the national level, dedicated to meeting the needs of people with disabilities, particularly hearing loss. In 1988, he was appointed by President Reagan to serve on the Architectural and Transportation Barriers Compliance Board, which drafted the accessibility guidelines for The Americans with Disabilities Act. In 1990, he was appointed by the Secretary of Health and Human Services to the advisory council of the National Institute on Deafness and Other Communication Disorders at the National Institutes of Health.

Since his retirement in 1975 from government service, Rocky has devoted his time and energies to the welfare of hard of hearing people. He founded SHHH in November 1979 and has been the volunteer executive director since then.

He comments: “I established SHHH as a membership organization run by people with hearing loss. We provide information necessary for them to make choices, but emphasize the choice must be theirs. The challenge is to develop togetherness within diversity.”

Today SHHH is the preeminent consumer organization for people who do not hear well. It is a volunteer, international organization of people who are hard of hearing, their relatives and friends. There are more than 300 affiliates meeting across the country, a national organization in Australia, and members in 15 countries.

A native of Cincinnati, Ohio, and born on March 3, 1925, Rocky and his wife of 41 years, Alice Marie Stone (Ahme), live in Bethesda, Maryland. They have two sons, two daughters and eight grandchildren. He retires as SHHH’s first executive director on June 15, 1993.