

Hearing MAGAZINE Loss

November/December 2012

IN THIS ISSUE:

Better Hearing,
Better Health

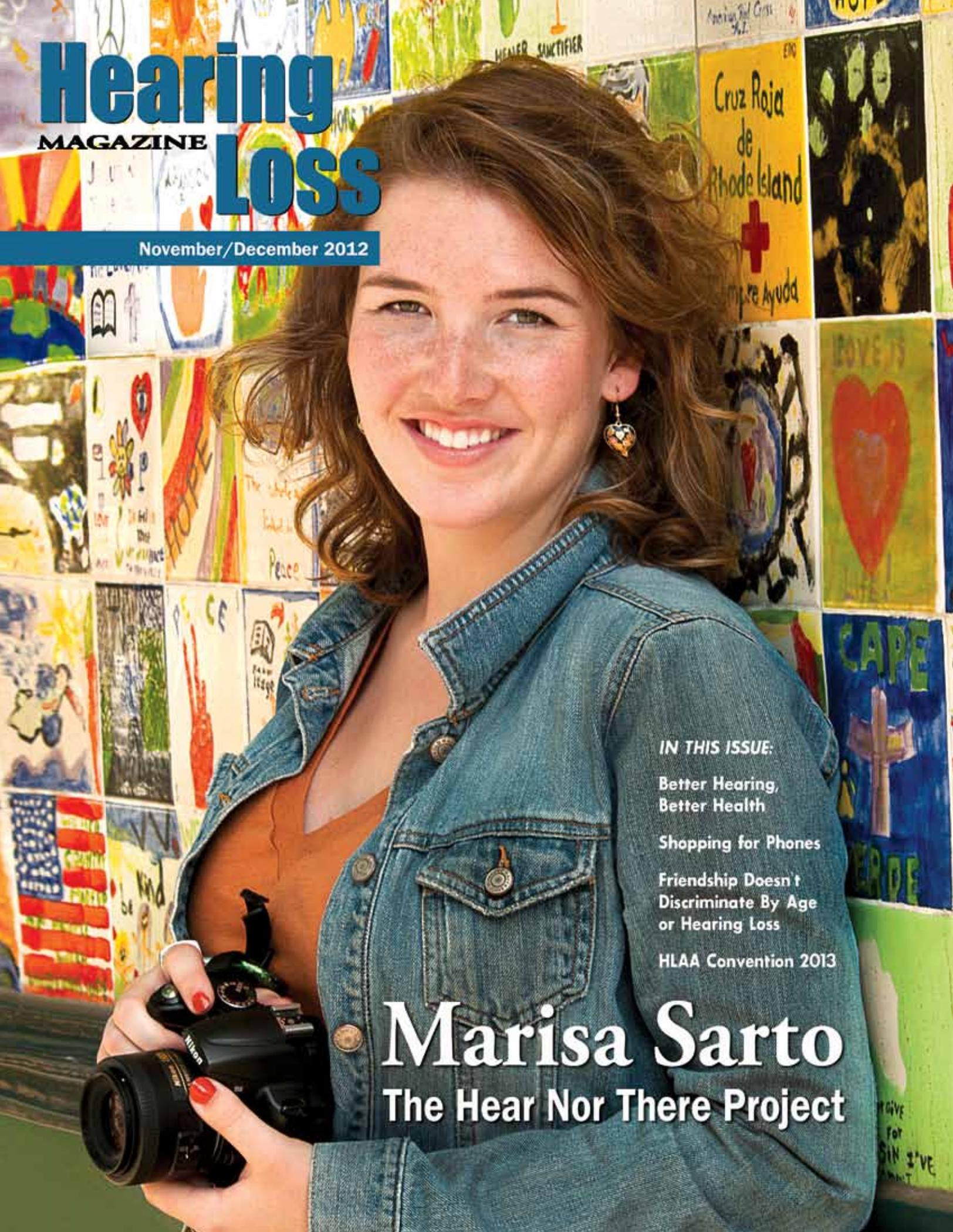
Shopping for Phones

Friendship Doesn't
Discriminate By Age
or Hearing Loss

HAAA Convention 2013

Marisa Sarto

The Hear Nor There Project



The Hear Nor There Project:

Much has been accomplished since 1979 with awareness, eradicating stigma, treatment, and legislation to ensure that people with hearing loss have full communication access in ways never dreamed of back then. Life has become accessible and, for some, easier, with advanced technology such as cochlear implants, state-of-the-art hearing aids, hearing loops and other assistive technologies, and captioning on TV and on the Internet.

Now, 33 years later, people still talk about living between two worlds of being deaf and hearing. Here, a young woman shares her experiences in much the same way as Rocky described it. She is embarking on a project to use her interest in photojournalism to express her theme of “Hear Nor There.”—*Editor*

By Marisa Sarto

I was born with moderate hearing loss. Soon after my first birthday, my small ears were fitted with their first pair of hearing aids. My brother and I both have a hearing loss; so I was fortunate that my parents were in a good financial place to afford hearing aids for both of us. My parents knew they needed to have a hold on the situation and didn't push my disability to the side. In elementary school they immediately enrolled me in a deaf and hard of hearing program which also allowed me to be mainstreamed once a day in a regular classroom. In addition, I received speech training regularly to improve my speech and listening skills. I couldn't have done it without the training and my hearing aids at the age of one.

One of my main challenges growing up with a hearing loss was acceptance by others. I was never a shy person. I loved talking and making new friends but I struggled with sharing the fact that I had a hearing loss. While many didn't mind, there were many who simply turned me down when I told them I wore hearing aids. That included people I wanted to be friends with and boys I liked.

At the beginning of middle school I wore my hair up almost every day; toward the end of middle school I wore it down every day. My young life activities included dancing, baton twirling, marching band, color guard, acting, drawing and designing. I loved performing; but performing with people on a stage in front of people was another challenge in itself.

I wasn't embarrassed about my hearing aids; instead, I wanted people to get to know me first. I wanted them to see that I was a creative artist and a performer. High school and college allowed me to fully love myself. I was taught in order to love someone else you have to love yourself first. With that I was able to build the confidence to tell people right away that I have a hearing loss because I knew it would allow me to fill my life with people that actually cared about me. I'm happy with the fact that I've been able to create connections, grow in understanding, make great friends and fall in love.

continued on page 11

When Rocky Stone founded this organization in November 1979, he talked about hearing loss as an invisible disability. Most specifically, being hard of hearing meant you were “between two worlds” as he described it. You were neither deaf and used sign language and felt at home within your community; nor were you fully hearing and had access to the world of complete sounds. He knew about being cut off from people, left out of conversations, because he experienced it and he expressed it in ways we could grasp.



Images of an Invisible Disability



The Hear Nor There Project

continued from page 11

Hearing loss greatly influenced my life and shaped my experiences. With my friends, family, education and career. While challenges—and successes—are common among many of us with hearing loss, deep within the colorful spaces of our world there is a gray area, perhaps a misfit place, for people who are hard of hearing. It is common for this place to be invisible to the perfect eye and unheard by the perfect ear, yet it is occupied by a live and vibrant community that, to an ability-driven society, appears neither here nor there.

Coping with Loneliness

I think loneliness is a huge problem in our world today. Anyone can experience it; any able-bodied person can feel alone. Then I thought what does it feel like particularly for someone with a disability; what could it be like for me? Yes, there have been times where I felt lonely because of my hearing loss. But I didn't want to feel lonely, but somehow I realized I was growing up and living life the way society taught me. But there was one problem—my society was not designed for me who couldn't hear every sound perfectly.



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The Hear Nor There Project

I'm older now and live in the real world and continuously think of new ways to change my society. After I graduated from college in 2011, I was concerned about my world and began to think about change. Did I need to change myself? My world? Or both? Then I did some critical thinking followed by what action I could take.

I first discerned what my realistic world is—a woman growing up with hearing loss often feeling self-conscious and set apart from others. I then thought about the scenario of this human drama, and then figured out where my talents might fit in to make a better place. I also knew whatever I did must make my heart sing, because nobody will want to do it with me if I'm not passionate and inspired.

That is how I thought of "Hear Nor There" project. We function better in the state of empathy, compassion and love than we do in the state of separation. I want my society to embrace each other in community. I want my project to create awareness, spread knowledge, and grow a community that we are not alone in this society. We are all connected.

My initial frustrations and early Challenges have grown into the belief

that many others who share similar experiences could collaborate and create a project that would show the hearing world—in words and with images—what it's like to deal with our little understood disability that shapes the day-to-day lives of us with hearing loss.

Having a view into our lives is relevant to the hearing world. David Cohen said it best in his book, *What Matters*: "Photojournalism works best when it's personal and specific but still conveys a universal concept."

My commitment to and connection with the hearing loss community has inspired me to create this unique photojournalism project. It is my hope that the photos and interviews will both represent people who live with this "invisible disability"—as well as tell many unique and compelling stories.

This project will be a documentary monograph, showcasing photographs and stories of individuals of varying ages, ethnicities and genders, and focusing on their challenges of living with a hearing loss. This project will present the nuances of those who identify more with the hard of hearing community as distinctly unique from the Deaf community. The renowned Gallaudet University Professor Jack Gannon explained that, "Deaf culture is a set of learned behaviors and perceptions that shape the values and norms of deaf people based on their shared or common experiences." I believe that this also applies to individuals who are consider themselves hard of hearing.

The hard of hearing culture and identity is distinct from the profoundly Deaf community. People with hearing loss who use their residual hearing have a common communication style. We share a strong reliance on speechreading with the support of technology, such as hearing aids, cochlear implants, and hearing assistive technology. Many of us also rely on captioning in order to enjoy everyday forms of entertainment, such as television, movies and live presentations.

People with hearing loss who consider themselves hard of hearing have unique lifestyles, yet our communication issues are much the same and speak

to the larger challenges and differences we all face as people who do not hear well in a complex and changing world. The motivation behind the Hear Nor There project lies in the desire to communicate that many people with hearing loss need technologies and resources in order to keep up with the normal pace of life.

Often, people who consider themselves to be hard of hearing feel misplaced by the hearing public due to a general lack of understanding of the related but unique struggles we face in comparison to those who live in the Deaf world.

Using text and photographs, I will guide the viewer through a visual journey representing individuals who describe themselves as hard of hearing from all generations who strive to maintain productive and exciting lives despite their hearing loss. I will also demonstrate how behavioral changes in society as well as shifts in the advancement of technological support work hand-in-hand to help improve the quality of life for individuals with hearing loss, their family and peers.

The photos will be of individuals or groups, in their homes, workplaces or social environments, interacting with family, co-workers and friends. The photographs will explore situations of both comfort and discomfort, joy or sorrow, with a focus on personal triumphs that might initially seem insignificant to the hearing public, yet which can be and are life affirming to many with hearing loss who are neither here nor there.

Subjects will be encouraged to discuss circumstances in which they have personally struggled, such as listening to lectures, participating in group meetings, using the phone, watching a movie, ordering in a restaurant, as well as situations in which their hearing loss was less of an obstacle and they could experience almost normal interactions. Through the personal stories of individuals with hearing loss, I hope to document quality of life issues such as financial challenges, effects on relationships and emotional health, embarrassing situations and lost opportunities. In addition to taking

continued on page 14

Marisa Talks About Joining the HLAA

About three years ago, I decided to commit my time and energy to working with the hearing loss community while I was attending the University of Wisconsin-Madison. I got involved with the Hearing Loss Association of America (HLAA) when I was invited to attend a state meeting in Wisconsin. Attendees all shared a desire to do something about the difficulties persons with hearing loss have to deal with on a daily basis. I was voted onto the Board of Trustees of the state association and I immediately became actively involved. I learned more about HLAA's structure and how the organization provided support for the hearing loss community.

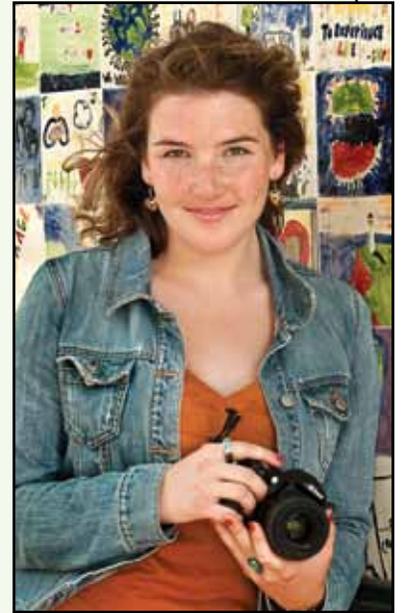
After being involved in the 2010 Wisconsin Walk4Hearing, it became my ultimate goal to start an HLAA Chapter in Madison, Wisconsin. Then, I was invited to attend the Leadership Training at HLAA headquarters in Bethesda, Maryland. The purpose of this training was to learn from and interact with organization leaders from other states and bring the knowledge back to Madison. I applied my knowledge in that community by helping to form the Madison Chapter more than a year ago with three local women—Carol Burns, Lisa Zovar, and Shelia Andersen. Together we organized monthly meetings for the Madison community. In these meetings, individuals were able to ask what others were doing to cope with their hearing loss and adopt or learn strategies for daily living. I realized that there is a great deal of useful information out there for individuals with hearing loss, and I wanted people to know about our chapter and see it as a place to go to for help.

I was able to attend the HLAA Convention 2012 in Providence, Rhode Island, on a Starkey Scholarship for first-time attendees. This convention changed my life, and I never felt more connected. I learned a great deal. Most importantly, I met many young adults like myself which I always wanted to do but never found anyone my age with hearing loss until I attended the convention.

I decided I want to help other young adults have this feeling of being connected and experience an HLAA Convention. With the other young adults at the convention, a group of us created a declaration. Our pledge is to welcome 100 young adults to the HLAA Convention 2013 next June in Portland through a campaign called 100 Portland. Our mission is to inspire creativity, collaboration, and committed membership among young adults with hearing loss around the country.

The 100 Portland campaign asks young adults with hearing loss to take action on their own behalf and to take responsibility for sustaining their own community presence at the HLAA Convention. Our mission is simply to unite Young Adults at the convention and from there, miracles will follow.

Editor's Note: *Read more about 100 Portland in the next issue of Hearing Loss Magazine. Visit the Facebook Page by searching 100 Portland Facebook Group, which is the official vehicle for driving this project.*



The Hear Nor There Project

continued from page 13

photographs, I will also conduct personal interviews and document personal stories, focusing on both tragedies and triumphs, such that readers will experience the world of hearing loss through our eyes and ears. Appendices, such as a list of resources for support or which may direct those who wish get involved with the hearing loss community, will comprise the final section of the book.

According to the Center for Hearing and Communication, approximately 12 percent of the United States population or 38 million Americans have some form of hearing loss. Through this exchange of knowledge, encouragement and shared experiences, I hope to empower the community of people with who sometimes call themselves hard of hearing and who don't use sign language as their main communication mode. (Although some choose to add sign language to their arsenal of communication strategies.)

The Decision to Do Something About Your Hearing Loss

I believe the decision to do something about hearing loss begins with understanding about what is happening to you. As the general public doesn't have a full understanding of the issues faced by our diverse group of people, I am committed to creating a transformational change in knowledge of our community through

photojournalism. It is my hope that this photo book will offer society a unique perspective as well as provide information, which together will create better awareness of issues close to the experience of hearing loss.

Every image will tell a story and celebrate the small victories and challenges that many people experience. One day, with each of us taking a step toward a better communal existence, the community of people with hearing loss who aren't fully hearing but are not Deaf, will no longer will be neither Hear Nor There.

Get Involved

To learn more about the project, go to www.marisasarto.com or e-mail Marisa at msarto@marisasarto.com. 

Marisa Sarto graduated in 2011 from the University of Wisconsin-Madison with a degree in film studies and is going an internship with the Lucie Foundation, a non-profit organization oriented toward photography. She attended college on a Posse Foundation scholarship. She says that her studies, combined with work in relevant internship programs, has given her a strong foundation. Marisa hopes to become a valuable asset to the world of photojournalism and is currently pursuing her passion—photography and photovisual journalism—in Los Angeles, California.

Learn some fun things about Marisa in her Seen & Heard profile on page 16.

Excerpts from Marisa Sarto's Hear Nor There Project

"Loss in Translation"—Most public transportation are not designed for those with hearing loss. Many avoid taking the bus, train or even flying. It's only in recent years that some travel information is being displayed in text. With that, one can still miss out on emergency information that's usually announced over the P.A., and that can cost someone's life.



"Lisa's nap"—Lisa Zovar (Wisconsin) takes a nap at her first HLAAs Convention in Providence, Rhode Island. With her hearing loss, she finds comfort in sleeping, but for many others with hearing loss might feel the opposite.



Marisa (far right, standing) with her friends in (grade here) caption here caption here caption here



“Dustin’s Rocket”—Dustin Scott, (24, California) life passion is in the performing arts whether it’s playing bass guitar for his band, acting on stage or filming & producing movies. Born with a hearing loss, Scott is living proof of what one can accomplish in spite of a disability. Scott’s view on his hearing loss is embedded in this tattoo. Scott says, “It’s a joke among my friends, that whenever they ask me to teach them a sign, I show them, “I want to become an astronaut.” It’s also a double meaning, the fact that the rocket ship is made of wood, it’s not going to work, but it’s the effort that you put into things that counts and that’s what I think of my hearing.”



“Mother-daughter journey”—Despite being born with CHARGE syndrome (a recognizable (genetic) pattern of birth defects which occurs in about one in every 9-10,000 births worldwide), Melissa Paredes (12, California) and her mother, both persevered through the obstacles they faced bringing Melissa to where she is today. Once told that she’ll never be able to hear or speak, Melissa proves otherwise, with the help of hearing aids, to lead an active life which includes baton twirling and playing soccer.

“Girlfriends”—These young girlfriends attended the 2012 Family Camp in Malibu, CA, put on by the House Research Institute every year. This camp provides an environment for both kids, siblings and parents to connect with other families that face similar issues surrounding pediatric hearing loss. For this group activity, the kids were asked to pair up, these two immediately held hands and were inseparable for the remainder of the camp.



“Carol’s Conversation— Visiting her mother, Carol Burns, (Wisconsin) wears a Cochlear implant (CI) and converse with her mother. It’s difficult however, with the air conditioner running in the background, the dishwasher on in the kitchen, and the T.V. volume on high.



“Communication Workshop”—A workshop is held at the Family Camp by the House Research Institute to encourage positive behavior as children see how rewarding it is to express daily kindness, appreciation, and love to all from an illustrated heartwarming book. Bullies abound no matter what the age and this workshop taught young children the power of words and to use those words carefully.



“Viral zone”—A leader in the HLAA D.C. Chapter, Viral Tejani is currently a graduate student at the University of Maryland, studying to become an audiologist. With an undergraduate degree in engineering, he felt it made sense for him to follow audiology to pursue his passion for clinical research. The combination of his engineering knowledge and personal hearing loss experience will allow him to contribute to the development of future technology. One place he is accepting of his hearing loss is at HLAA Conventions, during social outings with friends like Carrie Martin (Tennessee).

**Marisa Sarto
Seen & Heard
One Page to
come**

HLAA Celebrates, and Still Going Strong, at 33 Years!

Rocky Stone founded our organization in November 1979 as Self Help for Hard of Hearing People. The first issue of this magazine was published in July 1980 and was called the *Shhh Journal*. In each issue Rocky wrote an editorial under the intriguing headline, “An Invisible Condition.” These editorials gave visibility to the man and to the organization. They shaped the self-help movement in the field of hearing loss with a focus on the struggles, hope and aspirations of people with hearing loss everywhere. Beyond that, they were a look into a man’s soul who had a unique ability to portray the humanness of hearing loss with compassion and understanding.

A collection of his columns are published in his book, *An Invisible Condition: The Human Side of Hearing Loss* (SHHH Publications 1993). The book is out of print but it can be viewed online at www.hearingloss.org under “About Us,” click on Founder and click on link of book title.

To read about the history of the organization, go to www.hearingloss.org, click on “About Us,” then “History.”



“Between Two Worlds”—The Ambiguity of Partial Deafness

By Rocky Stone; Reprinted from the July/August 1985 Shhh Journal

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. ■■■