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# *Pacific Northwest ci Newsletter*

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Volume 1, Issue 2

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## **From the Desk of Dennis Clardy**

Here we are with our second issue of the newsletter. We have received our notification that we are classified as a 501(3)(c) non-profit organization. Thanks to all of the donors who have made contributions which will allow us to issue several more issues of this newsletter with the funds currently on hand. Please keep the funds flowing so that we may keep the spirit Gordon Nystedt started when he began this publication.

You will notice on the back page, we are asking for those who would like to receive this publication by way of the internet, please follow the instructions found there if you wish to participate in this method. If we have enough participants for this delivery method, we will make it permanent. Reduction in printing and mailing costs will help us keep our production costs low.

One thing is troubling; the number of individuals submitting stories is dwindling. Even though we may be financially able to publish, without material to print, nothing can happen. Gordon participated in various chat groups and was able to recruit from many sources. So, if you know someone who is considering a cochlear implant or has recently obtained their CI, encourage them to submit an article about their experience with their implant. Encourage everyone to contact us for information and support.

## **My Father-in-Law's Cochlear Implant Experience By Debbie Miley, Lyons, OR**

I have watched my father-in-law struggle with hearing loss for the past 15 years, and gradually it has deteriorated to the degree he did not really enjoy visiting anyone who was not aware of this problem. He had a hard time ordering at restaurants, and conversation in a car with all the background noise was almost

impossible unless he was looking at you and reading lips.

My father-in-law, Luther (Bud) Miley received his Cochlear Ear Implant on 7/26/01, and he chose to have the Clarion Processor. Due to a heart condition and medication it was a little tricky, but he was released to go home that same day. He experienced a lot of dizziness and nausea in addition to quite a significant amount of pain the first couple of days. During this period I believe he was initially sorry that he had it done, but as the days went by and the pain subsided, and the dizziness went away that feeling changed. In the two weeks that he was "totally deaf" it was obvious that he could hear even less. Thank God he had been deaf for the most part for many years and had mastered the art of reading lips. He also has a very limited amount of hearing in his other ear and was able to use that hearing aid.

Following the surgery, my in-laws were involved in an accident and Bud was somewhat concerned that he had dislodged the implant. However, a trip to the doctor assured him that all was well.

The day finally arrived that he would be "turned on", there was much anticipation on both my mother and father-in-law for this day. However, as they had been told repeatedly this was a process, a long process that required patience, therefore it was a cautious anticipation. He was given his first tones, and could hear the beeps. The days following the "Turn On", he experienced sounds that his brain recognized like water running, and he even looked behind him as he walked on gravel as he kept hearing a crunching sound and thought that someone was following him. So there was success, he was hearing sounds, but voices still were not understandable. He did experience a small problem. Due to swelling, he had a hard time keeping on his outside mike, as the magnet would not hold.

The day arrived for his second session with the great staff at OSHU.

Unfortunately that morning it was pouring and as he was getting ready and opening a garage door to the shop a surge of water shorted out his other hearing aid. He was quite upset at that, and attempted to dry it out, but to no avail. We took it with us to OSHU and they too tried to fix it with no luck. However they did get his "former" hearing aid for the implanted ear to work on that ear. As Bud went through the process for adjusting the tones in his implant, they were very pleased with the level they were able to up his tones.

They programmed two more programs for him to try and again reminded him that voices will take a while. He has not yet attained the high tones that are required to interpret voices. But I talked with him just a few days ago, and he seems very pleased with the new tones, and I think he just wants to hurry up and get them all. He looks forward to being able to visit and especially go elk hunting and hearing the sounds in the woods and on the river which is what he enjoys the most with all his children and grandchildren. He heard birds the other day and these are things he has not been able to hear for many years. He is very fortunate that he had hearing previously and his brain is assimilating these sounds very quickly.

Since that last visit, he has had a few setbacks that were discouraging at the time to him, he had a six week period where his hearing diminished again but discovered that his processor was bad, so he had to kind of start over. He was pretty discouraged but no choice but to move forward with the new processor. He again is now hearing better, but still not hearing voices, says they are still jumbled but we hope that will come with some continued patience and time. It has been a long journey for both my in-laws but we still keep hoping the long term outcome will be a whole new experience for them.

They have both praised OSHU and the staff there who has been so responsive and patient with both of them with their problems and really worked to encourage them.

## **Gordon Was a Source for Us All! By Allison Turner, Raleigh, NC**

Besides being a stand-in for Rocky Stone, Gordon was always to be seen at SHHH conventions talking to one or another of the participants who wanted his opinion on matters concerning hearing aids or cochlear devices. I was one of those lucky people who got to spend nearly one hour with Gordon in discussion of cochlear implants, as I was trying to make up my mind whether to jump in or to wait a bit longer in case there were new developments.

His advice was extremely helpful. I saw that waiting longer might not get me anywhere and meanwhile I would have another year or so without the help a cochlear implant could provide. I had already tested "positive" for an implant, i.e. I qualified, my loss was severe enough. Gordon gave some illustrations of how the implant had helped him and was careful not to push one brand of implant over another, saying both had their addicts, but that in his case he had chosen the Nucleus 22 for the reasons he gave. He had his life back and could never be grateful enough for that.

## **Partner of CI Individual Tells How Gordon Helped By Annette Bellamy Halibut Cove, AK**

I am the partner of a cochlear implant individual and I feel compelled as the main support person for this individual to share our story of Gordon. He was recommended as a very generous person in that he would answer questions and concerns for anyone who was considering an implant and network other's stories. We subscribed to his newsletter after the Clinic showed us several old publications of it. The newsletter alone was incredibly supportive in describing a wide range of experiences with implants. Finally there came a time when the decision was made for my partner to have an implant. There are decisions that follow the initial decision

that are huge. The biggest issue was whether to use the only good ear for the implant....that would take all hearing without an implant. This was a very difficult decision. There was a feeling to use the bad ear, despite the recommendations from the medical staff to use the good ear-this having 14% while the other ear was basically zero.

As the time deadline came up, I emailed Gordon and he immediately responded and firmly recommended that the good ear be used. He spent a lot of energy reinforcing this opinion and several exchanges convinced us that the good ear was the choice. He was an extraordinary support figure at this point and earlier in the process of deciding to go for an implant. We were grateful to have had his input and support. After several years, my partner's quality of life is much improved. Gordon was right on and the decisions made were not regretted. I hope this sort of support will continue.

## **Gordon Was A Fighter By Ben Gilbert, Tacoma, WA**

Gordon was a fighter - for the hearing impaired. One did not miss the intensity of his dedication.

Failure of the general population to understand the needs of hard of hearing clearly troubled him, motivating his dedicated advocacy. Conventional wisdom had thrust sign language on him. Much to his dismay, he found that it did not serve his life patterns.

Without denigrating the needs of members of the deaf community, he became a strong voice for those who considered dependence on sign language limiting. Ultimately, his cochlear implant became the liberating tool he sought.

Earlier last year, I turned to Gordon, a friend for nearly a dozen years, for advice on an implant. Would I be eligible? Was I too old at 83? Emphatically, he answered

"Yes," to the first question, and "No" to the second one. It took a battery of tests over weeks to confirm his instant diagnosis, made only a short time before his untimely death. My enthusiasm for the new CI echoes Gordon's who has left a void among us.

*Ed Note: Ben's story about his implant follows.*

## **Ben's CI Journal Highlights By Ben Gilbert, Tacoma WA**

Between 1983 and the dawn of the new century, I consumed five generations of hearing aids. Each new pair, touted as superior to the pair replaced, only served for a time. In the last two years, despite two top-of-the-line digital behind-the-ear aids, the drop in my ability to understand spoken language accelerated, virtually blotting out 80 per cent of the consonants.

Concern about the impact of the losing battle opened my mind to cochlear implant surgery, an option I had rejected. I turned to two friends, Gordon Nystedt, indefatigable advocate for the hearing impaired and Dr. Douglas Backous, medical director of the Listen for Life Center at Virginia Mason. I asked Gordon two questions shortly before his untimely death: Would an implant improve my situation, and would I be eligible? He fired back unequivocal "yes" responses to both questions. To Dr. Backous who had implanted older candidates as well as infants, I asked: "Was 83 too old for an implant?" To both questions he gave unqualified "no" answers.

The web pages of the three manufacturers offered solid upside and downside information along with product hype. Upside was winning. I made a formal request in March. The express bus took me back and forth to Seattle from Tacoma for demanding tests, consultations and evaluations. Underpinning a determination of "medical necessity," were scores needed to confirm that I would get no

further benefit from hearing aids, a governmental eligibility requirement.

With hearing aids, I registered 46% sentence recognition (speech discrimination) in my left ear and 26% in the right ear. The combined score of 47% highlighted the problem. I “got” fewer than half of the words. After administering the tests, Listen for Life Audiologist Robbi Bishop supported my candidacy. Dr. Fordyce, Virginia Mason psychologist confirmed that I knew what I was getting into; Dr. Backous cleared me as medically qualified. Medicare and Group Health would pay for costly surgery and installation.

Dr. Backous implanted the right ear, carving a niche in my skull for the quarter-size metal disc implant on June 13. Pain was moderate; healing took only a few days; touches of nausea disappeared quickly; balance returned soon thereafter. “Activation” of a Nucleus 24 Contour would occur in four weeks.

*On activation, Robbi asked me to track my progress in a journal. This account draws on the journal.*

**Tuesday, July 10:** An unspoken fear that it might not work vanished as Robbi “turned on” the implant after establishing levels for its 22 electrodes. The implant was transmitting understandable speech sounds to my brain! I clearly understood Robbi’s detailed technical explanations, although the sounds reaching me had a strange timber as if shouted through running water from a deep well.

On leaving the Listen for Life Center in Seattle, I heard birds chirp, other sounds of life I had lost. Rediscovered were leaves rustling, footsteps slapping pavement, wind blowing, and conversation buzzing. Back home, crumbling paper brought back a long forgotten noise.. Running water came across as a rushing flood. Keys tinkled unexpectedly. My impudent computer keyboard talked back. For the first time in years, high frequencies came through to me. As for the deep well, under water sounds, Robbi assured me that acceptable

“normal” sounds would emerge as my brain learned to accept the new signals. Old brains can learn new tricks, apparently. Fumbling with the speech processor, I managed a telephone conversation with my daughter Amy. She said she heard me speak at near normal volumes for the first time in years.

*These wondrous new connections banished “sounds of silence” that plagued me. Good riddance.*

**Wednesday, July 11:** To my delight, I functioned okay, successfully managing a series of shopping errands. At a luncheon meeting, I understood most of what the speaker had to say. At the Tacoma Landmarks Preservation Commission, I strained but was able to participate fully in the proceedings. TV listening with the basic CIS program was not a success. I did better with the more sophisticated ACE program, even better than with the two high-tech aids. I awarded myself a “B+” opening grade.

**Tuesday, July 24:** A retest of my ability to recognize words, phrases and sentences confirmed that I was hearing more and better. Robbi assigned “homework,” learning to listen. Practice with children’s tapes from the public library.

**Wednesday, July 25:** At a City Club luncheon, the speaker’s voice came across pretty well using the ACE program, although there was some resonance and sibilant sounds had a whistle. That afternoon, I was able to function effectively on the Tacoma Landmarks Preservation Commission in spite of missing some cross talk.

**Friday, July 27:** sitting face-to-face in a quiet restaurant with Moira Eicholtz, I heard virtually everything she said, better than I had done with hearing aids at meetings of the Tacoma SHHH chapter (Self-Help for Hard of Hearing People). A native of Scotland with a slight burr, she had been deaf for five years before getting a primitive version of the implant in 1983. Eventually a Nucleus 24 replaced it.

**Saturday, July 28:** On an afternoon waterfront walk, I became reacquainted with “environmental” sounds, the subtle background noises that hearing people

take for granted. I also heard approaching automobiles, a wind-like alert. To a casual comment about the beautiful day, I clearly heard a lady reply, “Yes it is.” That was an ultimate validation of the implant for me. My hearing aids had not delivered such “S” sounds in years.

**Friday, August 3:** Testing “listening” strategies has become a game. I’m adjusting sensitivity settings (the “bubble” that the speech processor covers). In noisy restaurants, I shrink the “bubble” to the table. In big meetings, the “bubble” is enlarged to bring in all possible speakers. The lapel mike helps with one-on-one conversations, the FM system in bigger rooms and places with poor acoustics. I’ve doing better with TV listening, although at raised volumes. My infrared system (Sennheiser) provides marginal improvement with the TV. I do best with “talking heads,” speakers facing directly into the camera. A speakerphone may be a better solution for telephone conversations than the plug-in amplifier supplied with the implant. It worked fine talking with Amy, my daughter.

*I’ve become easier to talk with, I’m told.*

**Monday, August 6:** Robbi put me through more training. Recommended strategies: Case out the situation including the lighting. Adjust the processor settings and sensitivity, listen aggressively. Don’t use a hearing aid in the un-implanted ear for three months; give the brain time to accept the implant signals. I had become easier to talk with, friend Michael Sullivan commented at a historic preservation event.

**Wednesday, August 8:** Dr. Ray Fitzgerald, my primary care physician, agreed that doctor-patient conversations have become less of a chore. I’m doing better with telephone calls; voices are climbing out of the deep well as predicted. For most telephone conversations, the speakerphone is adequate. When encountering difficulty, I hook up the implant amplifier as a fall-back.

**Monday, August 13:** The Tacoma Public Library provided a nine double-

sided tape of a biography of Colin Powell, the secretary of state. I'm hearing it clearly, reading along with the book. It is good "listening" training, more interesting than Peter Rabbit. Speech sounds came through on a tape with a noise overlay.

**Tuesday, August 14:** It was a struggle to overcome restaurant noise at the regular lunch group meeting, but sensitivity adjustments helped. At an evening Municipal League meeting interviewing City Council candidates, I did okay.

**Wednesday, August 15:** At a City Club luncheon, candidates on the Tacoma ballot had three minutes to make a pitch. Hooking the ALD to the public address microphone, I did quite well. Resonance and sibilant sounds are becoming less of a problem.

**Thursday, August 16:** It was busy with a business conference in the morning, a lunch meeting of a City Club committee and a civic conference in the afternoon. I managed okay. ACE has become the software configuration that works best for me. The lapel mike was useful.

**Friday, August 17:** Robbi modified the program settings, using ACE only. I now have three choices, Program 1 for general use, Program 2 for noisy situations, restaurants, etc. and Program 3 for telephone conversation. Program 4 carries the old Program 1, a backup. The changes are positive.

**Monday, August 20:** A session with Robbi, reviewing listening strategies, becoming more familiar with the controls. After a sentence comprehension test, Robbi sketched out a new audiogram, a more or less horizontal line in the 30 to 40 DB range. My unaided audiogram was a toboggan, vanishing about 1000 hertz, the high frequencies. Hearing the full range of sounds is exciting.

**Tuesday, August 21:** I maintained conversations at two restaurants, both noisy places, using Program 2 and adjusting the sensitivity.

**Wednesday, August 22:** I kept up with the presentations and participated fully in a complex meeting of the Landmarks Commission. The FM set gave me a small boost.

**Monday, August 27:** At an evening Municipal League meeting with 35 people seated around an enormous doughnut-shaped table, the FM placed near the chairman enabled me to hear his voice fine. I did not do as well with more distant voices. The sound is getting clearer, more "normal."

**Wednesday, August 29:** At a "workshop" Robbi conducted with me, I was reminded to tailor the processor's responses when using the telephone and FM system. Lower sensitivity levels reduces resonance and "wire noise (running water sounds)."

**Friday, August 31:** In the last few days, I probably made many telephone calls. At a Municipal League meeting in a big room, a conference FM mike on a stand in the middle of the doughnut-shaped table helped bring in speech from around the table. The chairman urged participants to elevate their voices and avoid simultaneous multiple conversations. I struggle less to hear, although I still miss some things. Thankfully, those times are becoming rarer.

**Wednesday, September 5:** To test strategies, Robbi and I lunched in the Virginia Mason cafeteria, a very noisy place. We reviewed progress and agree to test the value of a hearing aid in the other ear starting in mid-October. I did okay, using the lapel mike plugged into the processor.

**Saturday, September 8:** Twenty-five people attended the Tacoma-SHHH meeting to hear Robbi talk about technology, hearing aids, implants, etc. He provided a useful primer on the devices and strategies, evoking many questions. I did okay as chair, using the PA mike and the SHHH infra-red system.

**Wednesday, September 12:** Events of the last few days included a low-key political rally, a senior caucus meeting at Group Health, a regular weekly luncheon with friends, a historic preservation conference, a meeting with an ophthalmologist to explore cataract surgery and dinner with my daughter. I did fine generally, sometimes using the lapel mike. I had difficulty at the Group Health caucus when the speaker danced around the room, rarely holding any position for

more than a few seconds. I'm doing better, day by day.

**Saturday, September 15:** Well, it is time to assess the implant's performance. It has exceeded expectations. It was disappointing that the air traffic mess precluded appearance of the manufacturers' reps. at Thursday night's support group update on CI developments, but Robbi filled the breach. Robbi, as is his custom, repeated the questions before responding. I wish other speakers would do likewise. Two implants are probably better than one, he suggested, although research on that topic is still continuing. (Marcee Widland, the region's first double implantee, a Tacoma resident, has joined our SHHH group and will discuss her double implant as part of a program on implants in January.) The two are better than one idea raises an important question for me about use a hearing aid in the other ear. I'm comfortable with the implant, but probably will get a boost when I put a hearing aid in the left ear.

**Saturday, September 22:** Went to the Fifth Avenue performance of "A Little Night Music." The musical was a very funny farce played out in Sweden a century ago. I brought my own Sennheiser infrared receiver, the stethoscope kind, plugging it into the processor with an audio cable from Radio Shack. The Fifth Avenue has a very good sound system and infrared transmission. By reading the script in advance, I was able to understand the complex story while only hearing phrases. But, I did better than on previous theater visits, despite an overlay of running water type sound. Spoken words came across better than the songs.

**Monday, October 1:** The high point of the past week was a trip to New Hampshire for my grandson's wedding. I did not plug in the FM system. Regular settings plus the lapel mike worked pretty well. Airport and plane instructions over the speaker systems are often difficult, depending on how good the broadcast system is and the voice of the speaker. I asked my seatmates to flag me if anything untoward was announced. Thankfully,

nothing was. At the wedding, I had a seat in the front row, a short distance from the ministers and the happy couple. I heard most of what was said. At the dinners and receptions before and afterwards, I did okay with the lapel mike. Okay, of course, is relative, improvement over the hearing aids. The lapel mike worked well in the car, traveling some distance from the airport to a bed and breakfast establishment.

**Wednesday, October 10:** Robbi gave me several tests to measure improvement. I installed the hearing aid in the left ear. The dual system (implant and aid) seemed to work well, although the two sound sources tended to overlap.

**Thursday, October 11:** – I only had to ask for one repeat at a pre-surgery conference on removal of cataract in my right eye scheduled for Monday, November 5. Later, listening to President Bush at a press conference, I was able to reduce the volume and turn off the captions. TV cameras focused on his face, creating an excellent “speech reading situation.”

**Saturday, October 13:** Conducted the Tacoma-SHHH meeting. I kept up with Seattle Times medical reporter Warren King, the speaker, but depended on “real time” captioning for the questions from the floor. We had to turn off the public address system because of feedback problems. Someone had put a “live” hearing aid in his pocket! At a Tacoma Actors Guild performance of the “Sunshine Boys,” I did surprisingly well. Although the performance was not great, my hearing was!

**Sunday, October 14:** Although I am finding fewer occasions to use assistive listening devices, I acquired a Cochlear Co. FM cable, just in case. It produces less interference than the Radio Shack one I had used.

**Monday, October 15:** The lunch group met at a teriyaki restaurant, six of us. I picked up practically all the conversations, even parts of two simultaneous conversations. There were difficulties with rapid speech, the usual culprits. I did not use the lapel mike. Earlier, I had a telephone conversation with a stranger about a complex matter, but managed.

**Tuesday, October 16:** Attended two hour meeting of the Advisory Committee on Deaf and Hard of Hearing Services at TACID. It was less difficult than before I got the implant. Most of the attendees are deaf and depend on sign language. Two interpreters spell each other, voicing signs and signing voice. All the speakers including the interpreters were soft-voiced, but I did okay.

**Wednesday, October 17:** At a “debate” between the two surviving candidates for mayor of Tacoma, I followed the fast interplay, helped by a script of prepared questions. I probably got 80 per cent of the responses. In the evening had dinner with Amy at a noisy restaurant and did well.

*Yes, I am euphoric; the implant is becoming part of me!*

**Thursday, October 18:** I don’t mean to sound euphoric, but I am. I had two experiences today that spelled progress. The first was at the dentist. The hygienist gave me instructions as she worked without having to remove her facemask. The dentist commented: “I didn’t have to shout at you!” The second experience was at a study group meeting. I was hearing entire conversations and understanding well enough to participate fully in the give and take of the meeting, more extensively than I have done in years. I heard and communicated with two soft voiced people whose comments had often eluded me. It still is helpful to look directly at the speaker; sound projected better when I closed the door. The implant is becoming part of me!

It is my unprofessional judgment that I get as much as 90% of speech, almost double what it was before I got the implant. Robbi will have figures soon. What continues to amaze is the continuing day-by-day improvement in the quality of the speech sounds. I’m getting accustomed to them.

**Sunday, October 21:** I managed fine at the Listen for Life forum with the combination of FM attached to the implant processor and the hearing aid.

**Monday, October 22:** Robbi tweaked the programs and rearranged them.

Program 1, the general-purpose program, continues on ACE. Program 2 continues as the restaurant channel on ACE, but enhanced a bit. Program 3 will be for music and speech, a CIS program, set to emphasize timing, which should make music more understandable. It had been the telephone channel. Since Program 1 works well on phone calls, a separate phone channel is not needed. Program 4 is the old ACE program.

The results of the HINT test (sentence understanding) are sensational. 99% compared to a pre-implant score of 47% with hearing aids (46% in the left ear and 26% in the right ear). That is in relatively benign situations. On hearing in noise with the implant (without a hearing aid in the left ear), comprehension dropped significantly, but what else is new?

I’m hearing far better with the implant than I have in years, better than I had expected. I’m a lucky guy – grateful to those who have made this achievement possible. I’ve no intention to crawl into a shell.

### **My Experiences with Music and the Cochlear Implant** **By Bob Williams, Sublimity, OR**

I can’t say that I wasn’t warned. Everything I read, everyone I asked cautioned me not to expect music to sound the same with a cochlear implant as my natural hearing. “Your cochlear implant is designed to help you understand speech ... not music,” I was told by Nancy Cambron, my Audiologist. I had also heard and read that professional musicians threw in the towel once they received a cochlear implant.

Yet, I could hardly wait to try something. Perhaps my story would be different. The day I was hooked up, my wife Carolyn and I went to a large shopping mall near Seattle and I searched for the nearest music store. I found one with a wide variety of pianos and electronic keyboards.

I explained to the salesman my situation and asked if I could play

the piano. He pointed to a baby grand and said, "Be my guest." I sat down and began to play "Autumn Leaves", my arrangement of Roger Williams' arrangement. I chose it because the falling leaves fly from the top to mid-range on the piano. I could hear the highest notes, something I had not been able to do for years due to high frequency loss. But the instrument didn't sound like a piano ... it sounded like a twangy "Jew's harp".

I had much the same effect with the electronic keyboards. One positive thing in addition to being able to hear the high notes: the bass notes actually sounded like a piano and I could generally determine the key I was in from the lower notes ... at least I thought I could.

The following Sunday we went to church where I was exposed to congregational singing. The first hymn was unfamiliar to me and by the time I found the page, they were half-way through the first verse. What I read and what I was hearing were totally unrelated. It wasn't until they started the second verse that I was able to follow the music. Then it began to fall into place. I discovered that, if I knew the song, I could follow it. I could hear the highs and the lows and sing along with it ... at least I thought I could. But Carolyn nudged me and motioned for me to be quiet. I was singing in the wrong key. The other thing I noticed was that the key suddenly changed in the middle of the song in places where normal key changes are not made.

I tried listening to the radio and, although I could almost immediately enjoy news programs and talk shows, music didn't make much sense. My Kurzweil 1200 Keyboard was beginning to sound better, especially the lower notes.

One of the most frustrating things to me was that I could not hear the harmony. Only the melody came through on songs that I knew. I still did not enjoy listening to music on the radio.

One day as I was driving along and listening to Unforgettable Musica, I heard Nat King Cole singing, "Autumn Leaves". His voice sounded the same as I remembered it and I could hear the highs and the lows and I was almost too excited to drive.

The next day, I bought a three-volume CD of Nat King Cole's songs and took them home and listened to them on my computer. I used my patch-cord so I was able to get the music direct. The songs that I knew were readily recognized and enjoyed. Those I did not know or remember didn't make much sense. It was a huge pleasure to hear music once again by a recording artist that is still one of my favorites.

Not long after this, my cochlear implant was upgraded from the SPEAK program to the ACE. This vastly improved the sound of human voices putting them back in their normal ranges. Now, Paul Harvey sounded the same way I remembered him. This was true of virtually all human voices. And I noticed that when I listened to male trios I could make out parts at times on songs that I knew. Songs that I did not know continued to be monotonous with only melody. I have never been able to hear more than four to five pitches when listening to unfamiliar music.

My ability to hear and identify songs that I knew, however, continued to improve. Now I was listening to Frank Sinatra, Tennessee Ernie Ford, Perry Como, Patti Page, and Eddie Fisher. I bought a CD of "America's Favorite Marches" and enjoy listening to "Stars & Stripes Forever" and other familiar John Philip Sousa favorites. It sounds almost normal. So did a CD my daughters bought me for Christmas of Louis Armstrong's Greatest Hits. This was a new style of music for me to try and it was delightful.

Most recently, I bought a CD of familiar Glen Miller Big Band

sounds. I enjoy listening to the music I know, but I am still finding that to stay with the tune, I have to concentrate on what I'm listening to.

My greatest challenge musically was about five years in the making. In the late '70s, I wrote a contemporary musical entitled, "Fulfill Ye My Joy". I set the first chapter of Philippians from the Bible and the first two verses of Chapter Two to music. The text is in the King James Version.

In the mid 1990s, I told a friend who writes and produces Christian dramas about the musical and he remembered having heard our Youth Group perform it right after I wrote it. We collaborated on it by having him write drama and pantomime to go with it. During the years we worked together on this, I was almost completely deaf and, in fact, before we got through writing and editing, I had to use dry eraser boards so he could write his communiques to me.

This past Spring, we put it on with Community Choir and Drama Team. The pastor of the local Baptist Church directed the music, my friend directed and produced it and I played the piano. For rehearsals, I patched my Personal FM System into my speech processor and the Choir Director wore the lapel mike so he could communicate with me directly. He could say, "Would you play the tenor part on page 45 and measure 36?" And I would do so.

We performed it twice to full houses. What a challenge! And how gratifying as it was well received.

Earlier this year, I attended my first major concert. My wife and I drove to the Canby Performing Arts Center to listen to the Stayton Community Chorus and the Western Oregon University Orchestra perform Mendelsohn's "Elijah". This is a very complex oratorio and it takes a skilled listener to hear all the nuances and intricacies. I was able to obtain a copy

of the music from one of the performers and I sat in the front row so I could read the notes.

I had sung this great work with several oratorio societies over a period of years, but it had been at least 30 years since I had done so. The orchestra overpowered the choir much of the time and it made it difficult to follow along. However, I found myself in many places singing along with them. The most outstanding thing to me was the soloists and the acapella sections. I could not restrain the tears as I once again heard the strains of "Lift Thine Eyes" in three-part ladies' harmony and, yes, I could hear the parts.

But so much of it was unfamiliar in sound. I remembered the text as I read through it, but was hard put to make sense of the music. Imagine my surprise when a few days later, the tune began to return to my memory of many of the songs I could not identify at the time. Again, I could not restrain the tears, nor did I try. What a magical moment!

### **A Few Observations**

1. The electrodes only produce four to six tones. The brain fills in what the electrodes do not produce. This is also true of harmony. If you do not know what to reproduce, it doesn't happen.
2. The simpler the music, generally the more enjoyable.
3. The more percussive the piece, generally the easier it is to understand. Strings and large choirs become muddled. I find that a capella singing is much more identifiable than singers that use accompaniment.
4. Using the patch-cord with your CD, tape player or radio brings the music directly to your ear and is more discernible.
5. Certain instruments sound better than others. Trumpets are great. Pianos work quite well. Banjo is great, but I have yet to hear a guitar that makes sense.
6. I personally find that tone placement with my voice is virtually

impossible. What may sound like the right key to me is just plain wrong. And the higher the pitch, the worse it gets.

7. When playing the piano or keyboard, it often sounds as though the right hand is playing in one key while the left is in an unrelated key. This calls for heavy concentration as you try to tune out what you are actually hearing while at the same time conditioning your brain to recall the way it used to be. Sometimes it works and other times you simply have to live with it. I have only had one occasion where I simply had to stop in the middle of a performance because I was thoroughly confused. This afforded me an excellent opportunity to explain the differences in the way a cochlear implant reproduces musical sounds.

### **A Parting Thought**

I was attending a large church camp meeting where somewhere between 1500 to 2000 people were gathered. A choir from a Russian church and another choir from a Spanish church joined together in their respective languages to sing, "How Great Thou Art." That vast assembly was asked to join in on the last chorus. I was sitting there feeling sorry for myself because I simply could not match the pitches of those around me. But when we came to the chorus the first words were, Then sings my soul ...

"That's it," I almost exclaimed out loud. My cochlear implant may impede my ability to determine the pitch I'm grasping for, but nothing can stop my soul. And best of all, my soul has been singing ever since.

### **Ears, Hearing, & Beyond Conference March 9, 2002**

This one day conference is presented by the Virginia Merrill Bloedel Hearing Research Center at the University of Washington. Attendance is free. This is your chance to ask the experts. The program includes research and technology, panel discussions, and an exhibit hall. For more details check the website: <http://depts.washington.edu/>

### **Gordon Was My Oldest Newest Friend Sandra Bunning, WASA-SHHH Correspondence Secretary**

Gordon was my oldest newest friend. My first SHHH meeting - November 14, 1997 was when I met Gordon - you won't be surprised when I tell you I joined National that night - he just happened to have a membership form with him!

We were on the same flight heading for the Boston convention - always a gentleman - opening doors - even with a sore back he helped me with my huge suitcase, getting us the best table at the banquet and after the harbor tour he said "stick close to me" he knew just where to stand to catch the first bus - the buses were horribly late and we were all so tired - I did what he said and I was all tucked in bed when my roommates finally showed up.

He was all dressed up in his dark suit and looked so nice at the University of Washington conference in April - I told him so too - and oh you should have seen him blush. Several times I would hear some of you say - we'll ask Gordon - he'll know the best way - and when we would think of changing something - many of us would say - "Don't tell Gordon!" Volunteering like I do now at state level now, I realize how many it takes to fill one man's shoes.

### **Katie Cook gets an Implant Jim Cook, Salt Lake City, UT**

Our heartfelt thanks to Dr. Shelton and the team, the University of Utah (my work) and the insurance people who worked together to make our Christmas wish come true.

We apologize for not getting back to you sooner after the first meeting of the SL Chapter of the CIAI, but shortly after that meeting we became extremely involved (as many of you) in the Holidays and everything.

For us it also became a time of preparation and as the subject line suggests, our daughter Katie had her implant surgery the day after Christmas. Dr. Shelton informed us it "couldn't have gone any better". He said that they achieved "full insertion" and all went well.

As for Katie (our daughter) she is doing great. She had a rough time for a couple of days (we struggled getting her to take the medicine), and a good "shiner" (only one black eye) for a day. But as of today (almost one week) she is acting very much like normal (next time we are going to see if we can get a chip to settle her down just a bit), and we have not had to use but a small bit of the pain medicine. She is "one tough cookie", and we are very anxious to get started on the therapy and everything else.

Hope you all had a good holiday and hopefully 2002 will be even better. More to come, Jim and Julie Cook (and our CI daughter Katie)

### **Gordon Nystedt Was My Mentor** **By Pat Jordshaugen, Bellevue, WA**

Gordon Nystedt was my mentor. I thought of him as a close friend even though I only met him once in April 2001 at the Ears Hearing and Beyond Conference.

I have a profound hearing loss so I went to the conference to learn about new hearing aids and came home very excited because I learned about Cochlear Implants.

I met Gordon as he was handing out literature about implants and the upcoming convention. He was so encouraging about his implant and answered many of my questions.

A few weeks later I emailed Gordon telling him I was a candidate for the implant and asking him for any information he could give me about his experiences with the CI. He emailed back in less than two hours and not only told me his story

but forwarded my email on to several other people who have had the implant explaining to them that I would like any information they could give me.

I got many wonderful emails from so many nice people. I was greatly encouraged and decided to go ahead with the tests required before the implant.

During the next few weeks Gordon and I emailed each other several times about my progress. He was so funny because more than once he asked me when my surgery date was set to happen. I hadn't completely made up my mind if I was getting the implant. I was going through all the tests necessary as I was heading in that direction.

In my emails to him more than once I told him how much I appreciated all the help he had given me. He was like my own personal one man cheering squad!

The night before he died he sent me an email around 7PM asking me how my cat scan had gone and again asking me when I was set for surgery. I emailed him back later that night telling him my cat scan looked good and I had to get my balance test next. I still didn't know about the surgery date. In my email I thanked Gordon for all his help and encouragement. How much I appreciated all he had done for me giving me hope that maybe a CI would be my own little miracle.

I don't know if Gordon had a chance to read my email before he died the next day. I hope he did, but even if he didn't I know he has helped so many people with the huge decision of getting a Cochlear Implant. How can he not know what a mentor and friend he has been to so many.

I have kept all of Gordon's e mails to me and I will keep them always. I still need his encouragement. During the testing process for the implant

I had to change doctors because of insurance coverage problems. I am still in the testing process and have a few more tests to complete before I make my final decision.

### **Gordon Got Me On The Road** **To A Cochlear Implant** **By Jerry Olmstead, Anacortes, WA**

Gordon...we first met at a SHHH meeting in Anacortes. My wife took notes which I read during the meeting. At that time I had virtually no hearing. Joanna commented to me that I should be looking into a CI given the ability to hear and understand that Gordon demonstrated with his N22. Proceed I did, being implanted in October 1999. Gordon was there for me with his insight during that one month period were I was without any ability to hear...no residual hearing. Gordon was there as I adjusted to world of sound, providing words of encouragement and suggestions on how to grow to tolerate the areas of noisy environment.

Our relationship grew and he would contact me about my experiences. He used me as extension of himself in establishing a dialog with prospective CI individuals. In the spring of 2000 I helped Gordon and the many other CI's man the booth at the "EARS" conference at the University of Washington. It was remarkable to talk with the many people that he had helped in their quest to learn if the CI might be the answer to their own hearing lose. And the many spouses and friends of HOH persons which he helped in dealing with the issues of communication.

Gordon was also of great assistance in helping me deal with Cochlear Corp. when my BTE was not working and the corporations assistance was less than stellar. At the time of his passing he was working a meeting with the manufacturers and implantees, so that we could improve our dialog.

At the 2001 "EARS" conference at the University of Washington, I again helped Gordon with the CI booth. I ended up working with Gordon most of the day. He espoused his feeling about the current state of the multiple groups representing the HOH. It was enlightening to me to gain knowledge from his broad base of experience.

Gordon is not a replaceable asset in our community of HOH individuals. Each of us has to help carry on the traditions he established in helping one another. Let's step up and help those who are now trying to carry on with the Newsletter and counseling that Gordon established.

### **It's Tough To Take The First Step By Barbara Orr, Salt Lake, UT**

Thanks so much. Thanks also, for taking on this monumental task. I mailed Keith the newsletter I just received, so he'll be getting two now. He does have e-mail and I've received a couple from his wife, but I didn't keep the address, figuring if they wanted to get in touch, they would. I can get it again easily if you think I should. I can ask them if they'd like to be in contact with other people. I've never met him and they just live up the hill from me. The audiologist at the University of Utah asked if I'd get in touch with him and his wife because he had several questions and was looking into it. I've talked to his wife on the phone and via e-mail, but she said he's really dragging his feet. SHE is so excited about the implant, but he's very hesitant and I can certainly understand that. One article in this month's newsletter was especially appropriate for him and I particularly mentioned that to them...the one about "Nearly Missed Out" and Gordon was very blunt with him about getting it. I've also given them the name of a guy in Layton to call that would be very good to talk to and, being a male, might be better for him. I don't know, but the ball's in their court now.

I am from the Blackfoot/Rexburg area in Idaho—still my home and stomping grounds. I was intrigued when I realized some time ago from

the newsletter that someone from little ol' Buhl was implanted.

*(Ed note: My wife Catherine is the implantee in this family. She has a Nucleus24 and is anxiously awaiting the new 3G BTE so she can have ACE as her program for the BTE. Buhl, ID is located on the Snake River about 28 miles from Twin Falls, ID to the east and about 100 miles west to Boise. Buhl is the "trout capital of the US" as a result of many springs flowing in the area which provides ideal conditions to farm raised trout. Over 90% of the trout served in restaurants and supermarkets comes from the Buhl area.)*

I've also wanted to ask, did Gordon die from a heart attack? I'm assuming he must have since it was so sudden. He was a jewel, all right, and will be missed. I could tell he helped sooooo many people. I met him at the convention in California in '99, but that's about all I had to do with him. I really only take the newsletter to keep me up on what's going on in the implant world and keep me abreast of all the new technology that keeps coming out. But he was a very special, caring individual, one that this world needs more of.

I'm one of the "old" guard, having received an Ineraid back in '88, so I've been implanted for awhile and upgraded to the Med-EI a few years ago. Good riddance, Ineraid! I just received the newest Med-EI CIS-PRO+ processor last month in North Carolina.

Thanks for all you do. If I can help out at all from here, I'm certainly willing.

*Ed note: Gordon died of a heart attack.*

### **He Made Such a Difference By Sally Rudnick, Gresham, OR**

Gordon made a tremendous difference to so many of us CI people. I was saddened by his passing and was sorry to not have been able to thank him for the courage he instilled in me to go for the implant.

I am a single parent of an 8 1/2 year old daughter. I teach 2 sessions of kindergarten with hearing children.

## **Thanks for Your Support**

It is through our reader's financial support that we are able to keep this newsletter going. Following are those who have contributed:

Gordon Nystedt Estate, Kent, WA  
 Janet & Roger Pearce, Anacortes, WA  
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 Duane Sorensen, Corvallis, OR  
 Karen Burton, Kennewick, WA  
 Virginia Dagley, Wausau, WI  
 Archie Roberson, Meridian, ID  
 Marilyn Beach, Des Moines, WA

Out of the 54 students, over 30 do not speak English. I have an assistant to help me "hear". The implant has truly improved my quality of communication.

It is my hope that I will be able to help someone who has concerns of the implant.

**Dennis Clardy**  
**Pacific Northwest CI Newsletter**  
**P.O. Box 627**  
**Buhl, ID 83316-0627**



*Gordon Nystedt  
at Manhattan Beach  
CIAI Convention- 1999*

*We are interested in determining how many of our readers would like to receive this newsletter via e-mail. It would arrive at your e-mail address as a PDF format. The file attachment would be about 75Kb in size and could be read with the use of the free Acrobat Reader software program. It could also be printed on your local printer. If you are interested in this program, please send a e-mail message to us. In the message header show: EMAIL NEWSLETTER.*

*Then in the message, indicate your name and mailing address so that we know that your newsletter is not to be mailed. Be sure to e-mail us from the address that you wish the newsletter to go to. Our e-mail address is: [clardy\\_consulting@msn.com](mailto:clardy_consulting@msn.com).*

*The next newsletter will then be e-mailed to you as a test. If this proves feasible, we will advise everyone of the results.*

*Dennis Clardy  
Mary Steinmeyer*

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