



Hearing MAGAZINE Loss

July/August 2011

IN THIS ISSUE:

From a Body
Hearing Aid
to a Cochlear
Implant

A Look Into the
Mind and Heart of
a Caring Physician

Jury Duty:
Will You Serve?

Ulf Nagel

*From Silence to Sound:
My Quest to Hear Again*

From Silence to Sound: My Quest to Hear Again

Our social networking sites have connected people around the globe and our world has become smaller through the process. That's how we found Ulf Nagel from Norway, who maintains a blog with regular entries about his hearing loss. He shares his personal story and finds support. While not a substitute for face-to-face contact, blogs allow people the freedom to be more open in order to find encouragement and support.

Gabriel, Mette, Oskar and Ulf

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By Ulf Nagel at told to Hershel M. Dyer

Our Norwegian National Day is commemorated each year on May 17. I was delivered on that day in 1972, and I have been told that my birth was heralded by the rousing sounds of a marching band passing by the hospital. I have also been told that there was a severe complication in the delivery. The umbilical cord was wrapped twice around my neck, and the lack of proper blood flow during my birth could perhaps have contributed to my hearing loss.

In my second year of life I was stricken with scarlet fever, an infection that can also affect one's hearing by destroying the eardrum and damaging the middle ear bones. I was almost two years old before my parents realized I had a serious loss of hearing. I had not developed any speech, and, in one instance, other children and I were running when my mother shouted to me from a third floor window. The other children stopped when they heard her voice, but I kept running because I hadn't heard her calling me.

Memories of Being Different

My first clear memories of being different than other children are those of my first days of school when I was seven. The first year of my education in a public school was unusual because my mother was my first teacher. The only alternative in 1979 would have been to enroll me in a special school for deaf children and for those with severe hearing loss.

My mother wanted me to face the same challenges the other children faced, and later during those elementary years she secured help such as extra tutoring, carpeted classroom floors and microphones to enhance the teacher's voices. Her actions and her support helped me learn and create my self-identity in a normal world. Had she chosen the path of least resistance for me—a school for deaf children—I would be living in a very different world. I am now 39 and although I have much more to prove

to myself and to the rest of the world, my life to this point has been interesting and profitable in personal growth.

I went through my early school years much as other children did. I was somewhat withdrawn but I made friends and enjoyed those years. Some of my friends were into rock music and I soon joined them, and even let my hair grow long. The rock music lyrics helped me learn English and I remember those years with fondness. They were intense and pleasant times in my life.

Out in the Real World

I attended a boarding school for a year when I was 19. I thrived that year because it was my first opportunity to spread my wings and fly on my own. Then my life took a downturn. I enrolled in a school for Information Technology at the university level. I struggled, but managed to get through the first year. Socially I enjoyed it but academically and psychologically I struggled to the extent that I became ill.

In that year I suffered my first serious episode of depression. I didn't relate that to my hearing loss at the time, but later I realized that it was the beginning of a decline in my health and in my hearing. I knew the second year would present more demanding academic challenges and I doubted my ability to make it through successfully.

At this point I stepped away from academics and entered the work force. I married young at 23, and had several good years. In my working career I managed to work my way up the ladder to become a chief operational manager for an Internet programming/consulting company in the dot-com years. That ended with the dot-com crisis in 2001 and my world began to fall apart.

Blogging My Hearing Loss Journey

I began blogging in December 2007, and I have used that venue to document how profoundly deafness has affected my life. I also used the blog to track my efforts to obtain a CI

(cochlear implant), a surgically implanted electronic device that provides a sense of sound to a person who is profoundly deaf or severely hard of hearing. These blog titles and excerpts from them that follow should provide considerable insight into the problems presented by my hearing loss and the concerted search I made for help, a search that ultimately produced the desired results.

Ulf Blogs

When my ears hurt

(January 6, 2007)

Especially late in the day, my ears feel like they have been electrically overloaded, like a red-hot fuse about to blow. It feels like they're bleeding—literally. They are hot and sweaty, and I use cotton tips to wipe out the stuff that's in there. I do that because my hearing gets worse when the excess liquid in my ear canal actually dampens the sound that travels from my hearing aids.

Getting help

(February 18, 2007)

The department in the Norwegian state welfare agency that helps disabled people get a working life finally set me up for an appointment last week. Meeting someone who completely understands my challenges and my situation was a big relief.

A little upset—my political manifest

(March 2007)

Norway needs my skills and my work capacity. I have 10 years of IT experience, and a lot of IT certificates to my credit. Norway screams for more IT-skilled workers today! My working capability will improve. Just give me time and space to adjust and find my foothold and balance in life. And give me my CI operation now so I can exercise my communications skills without feeling like I'm committing a slow suicide. That way I can heal, recuperate and get back to normal work life a lot faster.

Nagging National Hospital, Round 1

(March 26, 2007)

This evening I sent a short e-mail asking them to respond and explain why it is taking so long for me to get the cochlear

continued on page 10

Ulf Nagel *continued from page 9*

implant. I told them that I have the time and the talent to contribute to society, that I am being forced to struggle for the surgery that can give me a better and more productive life. I told them that I'm ready now, that I'm prepared for the surgery and that I have the means and the motive.

Nagging pays off (April 13, 2007)

Last week I received the first letter from Rikshospitalet, the National Hospital located in Oslo, Norway, now part of Oslo University Hospital. They stated that I was eligible for a CI operation, and they guaranteed that I would get the operation before January 2010.

Un-hear

(May 21, 2007)

Still no reply from the hospital, and I'm growing more and more impatient. I'd like to have something to relate to—a future date for an examination, for example. I tried listening to music today and I had to turn it off—I just couldn't bear it. It felt like I was standing inside one of those old phone booths with a boom blaster at full volume and my ears stuffed with waxed cotton—far too much sound and far too little space.

From hard of hearing to deaf

(May 26, 2007)

My hearing for both ears is below 95 decibels. As the hearing declines, one becomes more of an outcast in social situations. It is difficult to cope with being somewhere with a lot of people laughing and rarely understanding why they are laughing. And when that happens over and over, I'm tempted to join in the laughter, faking it and pretending that I understand. That's a major part of social interaction—it's normal to want to be part of the group and want to interact.

Mentally drowned

(January 13, 2008)

It's a hellish place to be—like being forcefully drowned mentally. And because the transition to deafness is so slow for me, I have fallen in some kind of trap, by not being able to protect (get CI) myself in time. But here I am, and I have to take care of my son, myself, and keep on with my life. I know there is a solution for me up ahead with the CI, and it can't come soon enough! I have high hopes for 2008 to be the year when I either get word of when my first CI will be implanted.

Status update

(February 26, 2008)

Overall everything is a little bit worse. Tinnitus is loud, perhaps more constant, fatigue is a bit more severe. I get tired a lot faster from a lot less sound. Headaches are frequent. It's gotten to the point where I can't stand the sound of pretty much anything. I am now at about number 60 on the waiting list for the CI screening. About four months ago I was at the 100th place. If that pace holds, it means about 10 patients a month,

which means I could be looking for an appointment at around six months from now—August. I certainly hope so!

Second—and final pre-screening

(June 16, 2009)

Finally I will meet the CI team at Rikshospitalet and find out if I'm eligible for a CI or not. I have very few doubts in that regard, but have to prepare for the worst, of course—as well as for the best. Some days I feel great, everything is fine. Other days are like the world has been covered with steel wool. Everything is hard to grasp, hard to deal with, hard to get to. Even resting up is hard, but despite this, I'm able to keep my head up, my good spirit is never buried for long. I have much hope and a lot to live for!

On the operating table

(August 1, 2009)

I have a flash of memory arriving at the hospital, shaking hands with the anesthesiologist. A huge operating lamp looming over me...and a nurse preparing for the procedure. I said something, but can't remember what. I was really far out there even before the drugs. Tuned out. Then the post-op awakening. I couldn't believe I was already through it. For me it felt like I just dozed off from the pills. But I was gaining consciousness so slowly that at some point it dawned on me and I just felt relief.

Attitude, prejudice and ignorance

(August 18, 2009)

I have an assertion—I believe that most people with hearing loss are better listeners than many normal hearing individuals! Our (hearing disabled) minds twists and works the different possible meanings much more than they would in a normal individual's brain, because we have to

constantly question and confirm what we think we apprehended. Thus the process to understanding is more complex and thorough. I found this quote below (unknown origin) quite mind-provoking; it addresses something that needs to be discussed more. It's not only about what happens in the convergence between deaf and hearing, but also in universal aspect. It's about everything that is different from yourself and ourselves.

"If I had to put in a nutshell what is the worst thing about being deaf, it's not that I am not able to hear music. It's not that I am not able to hear a voice. It's not that I can't use the telephone. It's not that I can't enjoy a movie or a play. What is it then? Attitude. That's my biggest handicap. Not my attitude—your attitude."

Goodbye old life—hello new life!

(September 5, 2009)

Wow, I'm still here! More than four long years after the neurons in my brain formed the thought of getting a cochlear implant for the first time, I'm finally here. At the doorstep of a new reality. A new perception of the world of sounds promising improved social interaction and perhaps even music. It's time to walk through that door of perception, and shape my new world, and my life along with it. See you on the other side!

Learning to Hear Again

Life after the first operation has not been easy, but it has certainly improved. A while before the operation, I met my fiancée. She has been with me, for better and worse, during the arduous process of learning to hear again.

At the time of the operation, I had been living in a crisis-like state for nearly five years. It didn't seem like a crisis to me then, but in hindsight, I can't use any other word for it. Everything was difficult. Even talking one-on-one wore me out quickly. I could easily have become a social outcast. In social settings I tried my best, but had to rely on my lipreading skills and other means to compensate for the absence of hearing capability. Without my inner strength and the family and friends who supported me, I would

All About Blogs

A blog (a blend of the term web log) is a type of website or part of a website. Blogs are usually maintained by an individual with regular entries of commentary, descriptions of events, or other material such as graphics or video. Entries are commonly displayed in reverse-chronological order. Blog can also be used as a verb, meaning to maintain or add content to a blog.

Most blogs are interactive, allowing visitors to leave comments and even message each other via widgets on the blogs. It is this interactivity that distinguishes them from other static websites.

Many blogs provide commentary or news on a particular subject; others function as more personal online diaries. A typical blog combines text, images, and links to other blogs, Web pages, and other media related to its topic. The ability of readers to leave comments in an interactive format is an important part of many blogs. Most blogs are primarily textual, although some focus on art (art blog), photographs (photoblog), videos (video blogging), music (MP3 blog), and audio (podcasting). Microblogging is another type of blogging, featuring very short posts.

From Wikipedia, May 20, 2011

probably have gone under, or at least become permanently damaged.

I am somewhat disappointed by the Norwegian health care system. We have a long way to go and a lot to learn about sensory deprivation ailments. The health care system is doing a lot of good, but it suffers under bureaucracy and politics. It's the world we live in I guess—it's far from perfect. My story would have been very different if I had received a bilateral CI seven to nine years ago.

The operation was such a relief. Finally, I would get a chance for a comeback. I had tried all sorts of strategies for coping with the situation of becoming deaf—training in order to improve stamina, stop working full-time in order to avoid any more burnout issues, improving food and other health-related issues and so on. The list of changes I made in my life is really long. Literally every aspect of my life underwent scrutiny.

The uncertainty of getting the implant involved not knowing the outcome of the surgery itself, the process of recuperating, and most important, what the sounds would be like and how that process would turn out. As a complicating factor I

developed rather serious tinnitus in the years prior to the surgery. The implant itself was expected to help remedy that situation.

A Roller Coaster Ride


The process of learning to hear again has been a roller coaster ride. There have been moments of sheer happiness, joy and excitement of hearing sounds—some sounds I hear for the first time in my life. Some sounds are heard again that I had forgotten. And some sounds are familiar, but greatly improved in quality. And the greatest benefit of them all is being able to understand speech again!

The downside has been the quality of voices. It has been a bit like it was before the surgery—I had to work hard in order to utilize the speech that the brain recognizes. The sound of voices has a different pitch, but things improve when I start processing the meaning and context of the sentences.

Living with Tinnitus

The big bad wolf is my tinnitus, which is indeed suppressed by the implant but is still strong enough to disturb my brain's processing of speech. It's

continued on page 12



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“Frustrations aside, I consider myself very lucky now. I have had a resurrection in putting the pieces of my life back together. The important things in life are family and friends. My son Oskar has been an endless source of motivation and pride to me since his birth. The love, encouragement and commitment from my fiancée, Mette, and her son Gabriel have been wonderful.”

Ulf Nagel *continued from page 11*

odd the way my brain has become one of its worst enemies. Understanding the impact of severe tinnitus is almost impossible unless one has experienced it for a prolonged period. It is induced by stress and fatigue, and tinnitus in turn causes more stress and fatigue. It is literally a Catch-22 situation—you now have an idea of the dilemma I’m living with in terms of tinnitus.

Fortunately, there has been progress in the 23 months since my first implant. My brain slowly learns to utilize the speech comprehension center more and more. I’m improving in increments every day. I am able to understand everything from a simple conversation where I already know the context to comprehending someone without reading their lips. I am also able to use the phone.

Waiting is the Hardest Part

The thing that frustrates me the most these days is that I’m waiting for the second operation, bringing the grand total of waiting for a bilateral CI to six years! The other frustrating thing is that I’m still as vulnerable against fatigue and tinnitus as I was before the [first] operation. My theory is that one CI helped me improve my life, but the brain is struggling with the loss of audio-information from the other ear. I’m still tired almost every day, and I have yet to feel genuinely happy in a social situation with more than two people. I still miss music, but as long as I’m unilateral it will continue to be an awkward and exhausting experience.

My Strong Support System

Frustrations aside, I consider myself very lucky now. I have had a resurrection in putting the pieces of my life back together. The important things in life are family and friends. My son Oskar has been an endless source of motivation and pride to me since his birth. The love, encouragement and commitment from my fiancée, Mette, and her son Gabriel have been wonderful. They are the

most important people in my life and have made me feel human again, worthy of being loved.

The process of putting my life back on track started with the acceptance of the fact that I was deaf. The tormenting and tortuous process continued with extensive psychological therapy in several phases. And as a consequence of my own determination and the help I received, I found my capability to love and be loved again. My fiancée and I bought an apartment last year and we are completely refurbishing it. I am a handyman and I have had some time on my hands in the last six months to work on this big project.

As an added bonus, I have been able to start my own IT consultant company aimed at helping private citizens and businesses. I have limited work capacity but I’m honing my professional skills and preparing for a comeback, in the hope that my tinnitus and fatigue will subside with bilateral cochlear implants.

My life is back on track, and with the second implant there is no limit on how high I can fly! 🇺🇸

Ulf Nagel lives in Oslo, Norway. His blog can be found at ci4me2007.wordpress.com. He can be reached at ulf.nagel@gmail.com.

Hershel M. Dyer, aka The King of Texas, is a U.S. Air Force retiree with combat tours in Korea and Vietnam and also a U.S. Customs Service retiree.

Holder of bachelor degrees from Nebraska and Texas, the King relates, rambles, rants and rebukes incessantly with his autobiographical postings and cogent articles on city, state, national and world events. He posts his royal reflections and edicts for the pleasure and edification of his loyal subjects on his blog at www.thekingoftexas.wordpress.com.



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IFHOH World Congress 2012 to be Held in the Land of the Midnight Sun

June 25–28, 2012 in Bergen, Norway

Bergen, Norway, will play host to the International Federation of Hard of Hearing People for its World Congress. HLAA is a member organization. Founder Rocky Stone and past board of trustees members, Marcia Dugan and Mark Ross, have all served on IFHOH’s board.

A Better Quality of Life!

The theme for the World Congress in 2012 is *A Better Quality of Life!* Professionals and people who are hard of hearing will share their experiences through lectures, seminars and posters. The main language will be English and the Congress Hall will have all the necessary technical equipment and speech-to-text interpretation, so everyone will be able to understand what is being said.

The Congress starts with an opening ceremony and reception on Monday, June 25 followed by three days with an inspiring program, ending with a festive banquet on Thursday night.

The hotels will all be in the center of the town, just a few minutes’ walk from the venue for the Congress, The Grieg Hall.

A Lifetime Experience

This beautiful country, the nights when it never gets really dark, the meeting with people from all over the world, and an inspiring and exciting program will be something you will always remember.

Knut M. Ellingsen, president of the Norwegian Association of the Hard of Hearing says, “I can assure you that you will fall in love with the city which has many interesting sites and is surrounded by seven mountains. You can go by funicular from the center of the town to the top and get a wonderful view of the city and the fjords and the ocean. Bergen is in a compact, but lively center of town where you can reach everything by just a few minutes’ walk. Bergen, ‘The Gateway to the Fjords’, is a good starting point to explore the land of the midnight sun.”

Go to www.IFHOH2012.no for registration, hotels, tours, and more. 🇺🇸

HLA-Florida Call for Applications

The Hearing Loss Association of Florida (HLA-FL) is seeking qualified individuals to serve on the HLA-FL Board of Trustees for a three-year term beginning October 1, 2011.

Who is Eligible?

All members of Hearing Loss Association of America (HLAA) who are Florida residents are eligible. HLA-FL is committed to assembling a board comprised of individuals with a diversity of skills, backgrounds, hearing loss, and ages. Hearing applicants with sensitivity to the needs of people with hearing loss will be considered. Ability to work with others is essential. Positive thinkers with the desire to improve the quality of life for Florida residents with hearing loss are encouraged to apply. HLA-FL members can nominate themselves for board membership or nominate another Florida HLAA member (with permission).

What is Required?

The board meets at least three times a year in locations that vary to provide equitable geographic access. Members are encouraged to attend all meetings. Costs of travel are the members’ responsibility. Members are asked to take active roles on standing and ad hoc committees. Meetings are presently held on Saturdays to accommodate employed members. Major committee work occurs between board meetings and is most often transacted by e-mail or chat room, and thus, Board members are required to have e-mail access. Reimbursements of previously approved expenses on behalf of HLA-FL are available to trustees upon request.

How to Apply for the HLA-FL Board:

Application forms are available by contacting Lisa Tanner, Au.D, Nominating Committee Chair, 522 Oakfield Drive, Brandon, FL 33511 Call 813-315-9850, or e-mail lisatanneraud@adhs-brandon.com.