ANA/NJ
ACOUSTIC NEUROMA ASSOCIATION of NEW JERSEY

ANA/NJ Newsletter **Vol. XX, No. 1** **October 2023**

Special Notice from Wilma Ruskin, President of ANA/NJ, To My Fellow Recovering Acoustic Neuroma Survivors

♥

February 2, 1992, was the date that forever changed my life, as I knew it. I had 13 hours of surgery to remove a 2+ cm acoustic neuroma. Surgery that day was followed by years of intractable headaches , screaming tinnitus, at least three more surgeries, bacterial meningitis, forced retirement from a job I loved. And then a most wonderful part of my life began when myself and several other patients were called on [1994] to take up the job of restarting a local chapter of the acoustic neuroma association.

So for the last almost 30 years, ANA/NJ Inc. has been my life's work, as well as the total dedication of some of the hardest working fellow patients I've ever met. We have experienced the radical changes in treatment over these years, and have marveled at the amazing recoveries we've seen over the past few years.

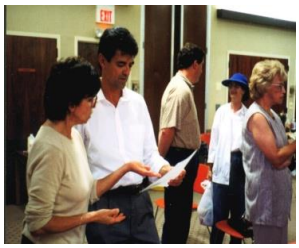
Our goals and our mission were always about providing information and support to our members and any others who needed our support.

Not only have I made lifelong friends through ANA/NJ, but I am so proud of our team and our organization. BTW, as a result of my personal involvement here, I have been a contact person for the American Tinnitus Association for more than 25 years and have also made several wonderful friends who have struggled with tinnitus.

So to wrap this up, this is to let you know that I am stepping down as president of this organization that I love with all my heart, and leaving it in the amazing hands of Dave Belonger, Jane Huck, Dick Barker, Donna Carides, Gaby Hecht and Kathy Cecere. Please support them and our organization.

I am about to start on my final project/conflict and could use your thoughts and prayers. Thank you all.

Wilma

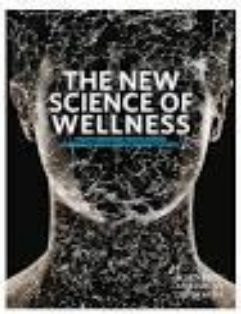


Wilma Ruskin, 1995

Notices!

● In her "Special Notice*"(above)*), what Wilma calls "my final project/conflict," is actually in reference to a serious medical condition making it impossible for her to give her best attention to the direction and needs of ANA/NJ. Dave Belonger, our long-time vice-president, has been elected to serve as president in her place. Dave has been using Constant Contact to design and conduct an important member Survey to help us decide on our future direction and needs of our association. We hope that you have received the Survey and will return your copy to Dave as soon as possible.

● Scientific American Custom Media has published *The New Science of Wellness -- Today's Medicine Treats Disease: Phenomics Could Stop It Before It Starts* (2022), available now online. This is a collection of updated articles that have previously appeared in the well-known science magazine. In his publisher's letter, Jeremy Abbate, harkens back to the year 2000 when the complete mapping of the human genome was celebrated at the White House (See "Genomics and Personalized Medicine," in ANA/NJ Newsletter, Sept 2, 2014). He observes: "Now we are on the next iteration of the post-Human-Genome era, using data-gathering bioinformatic tools to harness insights into the complex interactions of our genes, behavior, environment, gut microbes, metabolites and other disease-influencing actors." Leroy Hood, featured CEO of Phenome Health, writes about *A New Strategy for Keeping People Healthy*. "We now have the tools and the know-how to increase the number of healthy years a person can expect to live." Journalist David Duncan discusses *The Phenomics Revolution*: "Science is poised to shift the focus of health care to well care – the prediction and prevention of disease – rather than just treating the sick."



Thinking about "Hearing Preservation"

Probably a good way to begin thinking about dealing with a newly diagnosed acoustic neuroma (a.k.a.vestibular schwannoma) is to understand that it's a medical condition having numerous treatment options with different possible but not always totally predictable outcomes. The risks and benefits of its various treatment options need to be discussed with a specialist. "You will benefit most from a treatment when you know what is happening and are involved in making decisions. Make sure you understand what your treatment involves and what it will or will not do."[1]

Although still an elusive goal, treatment centers for acoustic neuroma are offering what is being called "hearing preservation." What exactly does this mean? If offered "hearing preservation" treatment, two main questions need to be asked, namely: (1) what level of hearing may be preserved, and (2) for how long may this level of hearing be preserved?

The Evidence–Based Guidelines on Hearing Preservation Outcomes in Patients with Sporadic Vestibular Schwannomas issued by the Congress of Neurological Surgeons reported (2018) that there is a "moderately low probability" (>25%-50%) of "serviceable hearing" preservation at 10 years following hearing preservation microsurgery or stereotactic radiosurgery. ("Serviceable hearing" is being defined as pure tone average ≤50 dB and word recognition score ≥50%). A "moderately low probability" (>25%-50%) of hearing preservation at 10 years was also reported for individuals choosing conservative observation (Wait-and-Scan) tumor management. Actually, there is a paucity of long-term hearing preservation data beyond the 10-year follow-up. There is agreement that patients with initially good hearing and smaller tumors have the best outcomes.

The two surgical approaches utilized for hearing preservation are the Middle Fossa for small tumors and the Retrosigmoid for both small and larger tumors. The third major surgical approach for acoustic neuroma, the Translabrinthine approach, is a "non-hearing preservation" approach utilized for very large tumors where preserving hearing is not an achievable goal.

There is a developing consensus that: "The best hearing outcomes occur in patients who are able to have their tumors simply followed with serial MRI scans. In these people, the hearing will remain the best the longest." In a North American Skull Base Society membership survey (2018), 51% of respondents felt that conservative observation confers the best chance of retaining serviceable hearing at 10 years in patients with small tumors and good hearing, compared with 42% for microsurgery and 7% for single-fraction radiosurgery. A study (2013) has reported that: "Durable hearing preservation a decade after low-dose SRS [radiosurgery] for VS occurs in less than one-fourth of patients." "One potential target for improving [radiosurgery] hearing rates is limiting [to 5 Gy] the radiation exposure to the cochlea." For large tumors following microsurgery, approximately only 10% of patients with tumors extending ≥15 mm into the cerebellopontine angle will retain serviceable hearing.

Neurosurgeons have complained that "hearing is such a fickle thing. If you can have [hearing] at the end of your vestibular journey, you're in a select group of people. Because the vast majority don't have it." "The hearing nerve is so exquisitely sensitive. You can't even look at it wrong and it will shut down, and so, the chance of improvement in hearing after surgery, radiation, any treatment is extremely low." "The truth and reality is that typically hearing will be lost over time."

---

[1] See "Discussing Health Decisions with Your Doctor," www.nia.nih.gov; and "Critical Decisions: A Look at Shared Decision Making," ANA/NJ Newsletter (June 2013). References for quotations in this article will be provided upon request.

"What is the Burden of Tinnitus?"

Researchers in the Department of Audiology at Aston University, Birmingham, UK, have published a study entitled "What is the Burden of Tinnitus?"[5] Thirty-nine in depth interviews were conducted (2017-2018) with 38 participants in southern England who were "help-seekers in a range of contrasting UK clinical services (Physician led, Audiology led and Hearing Therapy led)." Special attention was given to how these health services transferred work to patients for management of their long-term condition. An earlier study (2014) by Carl R. May and associates at the University of South Hampton, entitled "Rethinking the Patient: Using the Burden of Treatment Theory to Understand the Changing Dynamics of Illness," was of great value in the evaluation of the interview data.[6] The researchers state: "Relatively little is understood about the lived experience of tinnitus and no work has yet examined the work of living with tinnitus or the work of managing the interventions and help-seeking activities for tinnitus. This matters because clinicians negotiate the workload they give to patients and may be unaware of the impact of the treatment burden they create. We set out to understand the nature of the burden of illness and treatment for tinnitus."

Results: *According to the study participants, the illness burden of tinnitus is twofold. On the one hand, they had to cope with the interference of tinnitus in their daily life, and adjust their behavior so they could minimize the worsening of intrusiveness. On the other hand, they had to make sense of changes in self-perception following the onset of tinnitus, and this required additional work to digest the information surrounding tinnitus, i.e., that which was provided by health professionals and the information they found on their own. More importantly, participants had to translate such information into a personal and effective routine in dealing with the symptom. . We identified an overarching theme – the overcoming of negative self-talk fueled by self-judgment, frustration or anger. No definite answer could be provided about the course of tinnitus over time and how they will be able to deal with it on a daily basis. The participants had to discover it on their own, as well as the strategies that would work for them – among those that might have worked for others.*

Three subordinate themes were found to be related to negative self-talk. In abbreviated form:

Theme 1. Uncertainty arises from the process of help-seeking. Participants soon realized there was no straightforward cure that would help them get rid of their tinnitus. . . The lack of clear-cut information on the therapeutic outcomes was another source of uncertainty. . . "You read things on the internet and it's just like lots of scattered information" [*Patient 33*].

Theme 2. Dealing with tinnitus on their own results in a sense of abandonment. . . "The worst time is in the morning when it's very quiet and I've woken up at 5:00 sometimes 6:00" [*Patient 1*] *. . . The subjective nature of tinnitus leads to additional work for the patient who must convince others about the credibility of their distress. . Ultimately, participants who received no particular answer to their worries were driven to explore which routines would be most helpful for them.*

Theme 3. A sense of agency mediates patients' capacity to silence negative self-talk about having tinnitus. . . "You have to discover yourself, you have to discover what makes you relaxed" [*Patient 4*] *. . . "I bought this radio alarm clock and it had different sounds on it , sounds of nature, like waves lapping on a beach. I used to put that on at night"* [Patient *35*]. *"So you start to change your mentality, and you're in charge of your hearing. And you make your life better by learning about, and learning what is going to help."* [Patient *30*]. *A single dedicated clinician showing consideration for the patient outweighs a series of consultations with emphasis on technical investigations of tinnitus.*

---

[5] Helen Pryce et al, "What is the Burden of Tinnitus?" *Frontiers in Psychology*, Vol.13 (2022). Free full text copy available at pubmed.gov.

[6] BMC Health Service Research, Vol. 14 (2014). Free full text at pubmed.gov.

OTC: A Report in "*Reader's Digest*"

With the article entitled "Can Hearing Loss be Reversed?" by Canadian freelance journalist Venessa Milna, the popular family magazine **Reader's Digest** (May 2023) has joined in the discussion about the pros and cons of over-the-counter (OTC) hearing aids. It's a brief but informative article, written in the popular family magazine's upbeat style, positing that OTC aids "could act as a gateway for people who might not otherwise buy hearing aids – emphasizing that, according to one study, more than 80% of Americans with hearing loss don't wear hearing aids. Milna adds that worldwide, according to the World Health Organization, about 1.5 billion people have hearing loss, a number that could rise to 2.5 billion by 2050. We recall a Harvard study (2017) stating: "Hearing loss is the most common neurological disorder on the planet."

But Milna wants readers to know that the problem is not just about a lot of people not hearing well. The true impact is much broader than annoying poor sound recognition. She writes: "It's not just an annoyance, it's a major health issue." Researchers have been connecting poor hearing with other major health problems. She references the research of Dr. Frank Lin, director of the Cochlear Center for Hearing and Public Health at Johns Hopkins, who is currently conducting a control trial to see if wearing hearing aids can reduce the risk of dementia (See the Newsletter for October, 2022). It's being stressed that people who socialize less because of their hearing loss are having fewer cognitively challenging conversations with others, which increases the risk of dementia. Studies are also connecting hearing loss with problems of falling, sleeping, depression and vertigo.

Gene therapy for avoiding or remedying hearing loss is advancing. Milna reports on her interview with Dr. Richard Smith, the director of Molecular Otolaryngology and Renal Research at the University of Iowa. Dr. Smith uses a device called "AudioGene" to help predict genetic causes of hearing loss. He is optimistic: "I hope that people recognize that in the not-too-distant future we may have options besides hearing aids and cochlear implants." In Boston, the biotech company Decibel Therapeutics is one of the many companies researching hair-cell regeneration. The advent of regenerative medicine, says Dr. Jonathon Whitton, senior vice president of clinical research, has given scientists, health-care practitioners and patients "an emerging spirit of optimism." Milna comments approvingly: "New hair cells in the cochlea would mean that, instead of just turning up the volume of all noise, as hearing aids do, we'd be able to hear naturally and easily pick out speech from background noise."

In the meantime, as Milna describes, there have been major improvements in hearing aids that OTC can now make available without a prescription, and presumably at less expense. The big improvement is the ability of these "next-generation" hearing aids to automatically switch hearing modes depending on the environment.

Addendum: Milna ends her article warning that OTC comes with some caveats. For example, what if a person's hearing loss is caused by an illness that needs to be treated? We thought, yes, what if an acoustic neuroma (AN) is the problem? Certainly an AN patient would need special attention beyond what OTC service at the local pharmacy could provide. But we thought also that AN patients will benefit from OTC and current hearing loss concerns. ANers with single-sided deafness could benefit from a lower cost for the expensive CROS systems. Or success with hair-cell regeneration could help preserve hearing in the important contralateral/good ear. Also, AN by itself is a rare disease with minimal or delayed research support; but hearing loss being ranked as a "major health issue" should result in increased funding for genetics research to the ultimate benefit of acoustic neuroma patients.

•

The Brain: A New Discovery

One reason that there are not better drugs and treatments is that we don't know enough about the brain. . . We must realize that it may take 20 years for discoveries in basic neuroscience to lead to treatments and cures for brain disorders.

("Brain 2025, A Scientific Vision*,"* National Institutes of Health, *June 5, 2014*)

In the United States, the BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies) was launched on April 2, 2013, to develop "a scientific plan to discover how the brain actually works".[4]

It should help that researchers at the University of Copenhagen, Denmark, have discovered a previously unknown component of brain anatomy – "a membrane that acts as a protective barrier and a platform from which immune cells monitor the brain for infection and inflammation." Called SYLM (for subarachnoidal lymphatic-like membrane), the membrane "segregates and helps control the flow of cerebrospinal fluid (CSF) in and around the brain." Researcher Maiken Nedergaard notes that the membrane provides us much greater appreciation of the sophisticated role that CSF plays not only in transporting and removing waste from the brain, but also in supporting its immune defenses." The membrane is "ideally positioned to surveil the cerebrospinal fluid.

Some Early Treatments for Hearing Loss

"*Some for the care of deafness, recommend the gall of an eel, mixed with the spirit of wine, to be dropped into the ear. Though such applications may sometimes be of service, yet they much oftener fail, and frequently they do hurt. Neither the eyes nor ears ought to be tampered with; they are tender organs and require a very delicate touch. For this reason, what we would chiefly recommend in deafness is to keep the head warm. From whatever cause the disorder proceeds, this is always proper; and I have known more benefit from it alone, in the most obstinate cases of deafness, than from all the medicines I ever used."* From 'Disorders of the Ear,' in ***Domestic Medicine: Or, The TheFamily Physician*** (Edinburgh: Balfour, Auld & Smellie, 1769), by Dr. William Buchan, University of Edinburgh. Available online via Google.

• Stanley Finger, ***Doctor Franklin's Medicine*** (2006), p. 316, notes that it was common practice in Benjamin Franklin's day (d.1790) to use a ticking watch to measure how well a person could hear. The cupped hand to enlarge the hearing ear was also common practice, and still works today.

• David Cowen, ***Medicine in Revolutionary New Jersey*** (1975) is an interesting read. See also Harlow Unger, ***Dr.Benjamin Rush: The Founding Father Who Healed a Wounded Nation*** (2018),

---

[7] See "The Brain Initiative," ANA/NJ Newsletter (Sept . 2015.) "*Brain 2025. A Scientific Vision* " (June 5, 2014), presents (146 pp) the scientific plan to implement the Initiative. See www. braininitiative.nih.gov. See "A Newly Discovered Membrane Shields and Monitors the Brain," *Rochester Review* (Spring, 2023).

ANA/NJ In-Person Meeting
April 16, 2023

Fourteen people attended the in-person meeting on Sunday, April 16, 2023, at the Princeton Medical Center in Plainsboro, NJ. Because of earlier Covid restrictions, this was the first in-person get-together for ANA/NJ members and friends since the March 31, 2019 meeting at the Summit Health Center in Berkeley Heights.

There was an even split in the number of new and older ANers attending, which resulted in an interesting sharing of experiences with acoustic neuroma post-treatment problems. Considerable attention was given to the problem of dry eye**,** resulting from inadequate tear production and/or incomplete eye closure as a consequence of damage to the facial nerve and lacrimal gland during surgery. There was good discussion of available eyedrops, helpful moisture chamber goggles, and the use of upper eyelid weights for closure problems. There's much useful information in ANAUSA's booklet on "*Eye Care after Acoustic Neuroma Surgery*," (2018 edition), edited by ophthalmologist Dr. Robert Levine, University of Southern California.

A second main topic for discussion was hearing aids, especially the CROS/BICROS non-surgical options as by the Phonak or Signia systems. (See the Newsletter for October 2022 for Dr. Hillary Snapp's helpful review of the literature; see also ANAUSA's booklet entitled *Hearing Loss: Rehabilitation for Acoustic Neuroma Patients* (Revised edition, May, 2022).

South Jersey Proton Beam Center

Virtua Health and Penn Medicine have announced the opening of a $45 million proton beam radiation center located in Voorhees, NJ. We last reported on proton beam radiation in

Proton Therapy Center, Voorhees

the October 2013 issue of the newsletter after ProCure opened a North Jersey proton center in Somerset, NJ. To date, not many acoustic neuroma patients have had proton beam therapy because few facilities were available in the USA, and perhaps also because the treatment offered involved mostly conventional hyper-fractionation (30 sessions). Fractionated proton therapy (FPT) has been used mainly for larger acoustic neuromas (vestibular schwannomas) in close proximity to the brain stem. Theoretically, proton radiation makes it possible to maximize tumor control and the sparing of normal tissues. The Loma Linda proton center in California has reported on "Fractionated Proton Beam Therapy: Tumor Control and Hearing Preservation," *International Journal of Particle Therapy* (Spring 2018). Oncologists at the University of Heidelberg, Germany, have recently compared outcomes for SRS and FPT (*Cancers/Basel*, Vol. 14,April,2022).

Acoustic Neuroma Association of New Jersey
P.O.Box 6562
Bridgewater, NJ 08807-0562

Dave Belonger,Website Mgr
Marlton, NJ 08053
dbelonger@verizon.net

Dick Barker, Newsletter Editor
Frenchtown, NJ 08825
rjbarker@centurylink.net

Jane Huck, ANA/NJ Directory
Bridgewater, NJ 08807
janehuck@msn.com

Membership/Donation Form

Name_____
Address_____
City _____ State _____Zip _____
Phone ( ) _____ E-mail _____@ _____

Membership Categories

□ Annual Membership . . . . . $ 25
□ Life Membership $200

Contribution Categories

□ Sponsor a member $25
□ Associate . . . . . $10 – $50
□ Supporter $50-$200
□ Benefactor $200 & above

Membership dues and gifts are the main resources available to ANA/NJ to help us fulfill our mission to provide information, encouragement, and support to AN patients and their families. Please consider supporting ANA/NJ's endeavors by becoming a member or contributor. Thank you!

□ A gift in honor of: □ A gift in memory of:

Name _____

Please send an acknowledgement to:

Name _____

Address _____

Please make all checks payable to:

ANA/NJ
P.O.Box 6562
Bridgewater, NJ 08807-5007

All members will receive the news-letter, notices of local meetings, updates, pamphlets & other information.

For membership in ANAUSA

Acoustic Neuroma Association
600 Peachtree Pkwy, Suite 108
Cumming, GA 30041