

ANA NJ

ACOUSTIC NEUROMA ASSOCIATION of NEW JERSEY

ANA/NJ Newsletter

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February 2022

ANA/NJ Virtual/Zoom Meeting October 24, 2021

Twenty-six ANers and friends including all ANA/NJ Board members registered for our first ‘Zoom with Speaker’ meeting held Sunday, 1-3 pm, October 24, 2021. The topic was “Options for Better Hearing.” Our speaker and leader for the Q&A was Dr. Jed Kwartler, the Director of Otology and Neurotology at Summit Health in Berkeley Heights, NJ. Dr. Kwartler is a long-standing, dedicated member of our Medical Advisory Board. Many thanks go also to Board member Dave Belonger for arranging and moderating this special Zoom session.



Dr. Kwartler’s introduction with Power Point Presentation, as well as the following open Q&A discussion, made clear that “Options for Better Hearing” for acoustic neuroma patients is not to be thought of as a convenient list of available devices for everyone to choose from. It’s not a ‘take your pick’ list. Rather, the options are a continuum of rehabilitation, depending upon each patient’s special needs and circumstances, and ranges from conventional in-one-ear air conduction aids, to dual-ear CROS air conduction systems, to non-surgical or surgical bone conduction devices, to surgical cochlear

implantation (CI), and even the auditory brainstem implant (ABI). The technology is advancing rapidly. Dr. Kwartler called attention to two recent examples: the ADHEAR by Med-El, a non-surgical external adhesive bone conduction system (see the Newsletter, April 2020; and V. Dahm et al, “First Results with a New Pressure-free Adhesive Bone Conduction Hearing Aid,” *Otology and Neurotology*, Vol. 39, 2018); and the OSIA by Cochlear, a redesigned Baha bone conduction system with a very thin implant and no through-the-skin abutment (see the Newsletter, October 2020; and M.Goycoolea et al, “Clinical Performance of the Osia System, a New Active Osseointegrated Implant System,” *Acta Otolaryngol*, Vol. 140, March 2020), thus avoiding the Baha problem of skin abutment overgrowth.

For dealing with single-sided deafness, the Q&A showed much interest in favorable patient evaluations of the BiCROS system by Phonak that routes sound from the affected ear to the contralateral/better hearing ear. (We note that the Phonak company currently recommends a ‘CROS P’ for the poor ear to send sound to an ‘Audéo Paradise’ aid in the good ear.)

The currently proposed Medicare expansion for coverage of Over-the-Counter (OTC) hearing aids and audiology services was touched upon briefly. Maybe take a look at the helpful *ALDA News* articles on this subject on the website of the Association of Late-Deafened Adults (www.alda.org).

ANA/NJ

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of New Jersey

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Notices!

- For both the ANA/NJ Newsletter and our recently introduced Constant Contact (CC) emails, we welcome having personal 'Stories' of the acoustic neuroma experience as well as 'Notices' of any new information about acoustic neuroma. We want to stay in touch and keep up-to-date. Remember to send your email address to Dave Belonger (dbelonger@verizon.net) if you want to be on the CC email list.

- "The Connection" – the newsletter of the Acoustic Neuroma Association of Canada – is available to read by non-members. Go to www.anac.ca and click on Members, then Member Resources, and then Our Newsletters, for issues of the newsletter dating back to 1993. The Winter 2021 issue has an article entitled "Dry Eye Solutions and Acoustic Neuroma," by Dr. Angela DiMarco, OD, FAAO. She is Lead Optometrist at York Finch Eye Associates and Associate Optometrist at Toronto Eye Care. Dr. DiMarco describes the various treatments available for corneal dryness resulting from damage to the facial nerve and lacrimal gland during surgery for acoustic neuroma. While on the website, perhaps take a look at the Summer 2019 issue for Dr. John Rutka's thoughtful article "To Judy: A Letter with a Purpose : Further Insights in the Conservative Management of a Vestibular Schwannoma." Dr. Rutka is professor of Otolaryngology-Head Neck Surgery at the University of Toronto.

- The National Institute on Deafness and Other Communication Disorders (www.nidcd.nih.gov) warns that long or repeated exposure to loud sounds can cause hearing loss as well as tinnitus. How loud is too loud? Sound is measured in units called decibels (dBA). Sounds at or below 70 dBA are generally safe. Sounds above about 85 dBA can be hazardous. Here are decibel ratings for some familiar sounds:

Whispers	10 dBA
Normal Conversation	60-70 dBA
Vacuum Cleaner	81 dBA
Lawn Mower	80-100 dBA
Movie Theater	74-104 dBA
Motor Cycles/Dirt Bikes	80-110 dBA
Chain Saw	105 dBA
Loud Music via Headphones	94-110 dBA
Sirens	110-160 dBA
Rock Concerts	120-130 dBA
Fireworks show	140-160 dBA
Gun Shots	160 dBA

Current VS Management Practices in North America (NASBS Survey)

The North American Skull Base Society (NASBS) surveyed its membership to determine current practice trends and variance in treatment philosophies for VS. A total of 719 members were surveyed, and 57 completed surveys were returned by members involved regularly in VS treatment. Most respondents were between 50 and 59 years of age and all were men. Sixty percent were neurosurgeons and 40% were otolaryngologists. “Approximately three-fourths of the respondents claimed an academic practice setting, with over 80% evaluating at least 25 new cases at their center per year, and over 50% evaluating more than 50 cases per year.”¹

The study noted that surgeons who treated more than 50 tumors tended to utilize a multidisciplinary team more frequently than surgeons with less experience. There were significant patient benefits from specialized care at centers with multidisciplinary teams including neurosurgeons, ENT surgeons and neurotologists. “Higher volume centers frequently require a shorter length of stay and an associated reduction in inpatient costs.”

Regarding treatment selection for VS, the survey showed a “shift toward conservatism.” “Specifically, surgeons are more willing to perform subtotal tumor removal to mitigate risk of facial paralysis, and a greater number of patients are undergoing SRS/SRT [i.e., Radio-surgery/Radiotherapy] or observation. Between the late 1990s and 2012, several publications documented an upsurge in radiation use, and most recently the use of serial observation has

¹ M. Carlson, M. Link et al, “A Cross-sectional Survey of the North American Skull Base Society: Current Practice Patterns of Vestibular Schwannoma Evaluation and Management in North America,” *Journal of Neurological Surgery*, Vol.79(3) (June, 2018). Free full text copy at www.PubMed.gov.

become the fastest growing management strategy.² This recent transition toward observation is strongly evidenced in this study, where an astonishing 91% of respondents reported that at their respective centers most small (<1.5cm) VSs are managed with initial observation until growth is demonstrated. Furthermore, 51% of respondents felt that conservative observation confers the best chance of retaining serviceable hearing at 10 years in patients with intracranial tumors and good hearing, compared with 42% for microsurgery (32% middle cranial fossa, 11% retrosigmoid) and 7% for single-fraction radiosurgery. . . . Despite this clear trend toward initial observation, there appeared to be considerable variability between centers with regard to the ratio of cases treated with micro-surgery and observation. This variance in management between centers parallels findings from another recent study, implying that provider and institutional biases still significantly impact treatment trajectory.”

Regarding hearing preservation surgery for VS, the authors note that the ‘best’ surgical approach remains a debated topic. “In this study, we found that most respondents favored the middle cranial fossa approach for intracranial tumors when attempting hearing preservation surgery.”

Regarding radiation treatment for VS, the survey showed 63% of respondents used Gamma Knife; 25% Cyberknife; 25% Novalis LINAC; and 16% Proton Beam. Some centers used more than one type of radiation. The 16% for proton beam was noted as ‘interesting’ in view of little data regarding its effectiveness compared to SRS or SRT.

² See “A Shift Toward Conservatism,” ANA/NJ Newsletter (March 2019)

Gene Therapy ‘Coming-of-Age’

Researchers in the Department of Human Molecular Genetics and Biochemistry, Tel Aviv University, Israel, have reported (2019):

More than 15 years have passed since the official completion of the Human Genome Project. Predominantly due to this project, over one hundred genes have now been linked to hearing loss. Although major advancements have been made in the understanding of underlying pathologies in deafness as a consequence of these gene discoveries, biological treatments for these conditions are still not available and current treatments rely on amplification or prosthetics.

A promising approach for developing treatments for genetic hearing loss is the most simplistic one, that of gene therapy. Gene therapy would intuitively be ideal for these conditions since it is directed at the very source of the problem. Recent achievements in this field in laboratory models spike hope and optimism among scientists, patients, and industry, and suggest that this approach can mature into clinical trials in coming years.

Gene therapy for deafness and hearing loss is currently coming-of-age. Recent developments in viral-vector technology [for delivery of therapeutic genetic material into cells to treat genetic mutations] have led to a dramatic increase in manuscripts reporting successful rescue in animal models of human hearing loss. This exponential growth in gene therapy literature has not gone unnoticed by the pharmaceutical industry, and almost 50 bio-technology and pharmaceutical companies are currently developing therapeutics for inner ear and central hearing disorders. AGTC [Applied Genetic Technologies Co.], Rescue Hearing Inc, and Akouos are three companies currently engaged in pre-clinical testing of AAV [Adeno-Associated Virus] to treat genetic hearing loss. Similarly, Casebia Therapeutics, a joint venture between Bayer and CRISPR Therapeutics, is conducting pre-clinical testing of CRISPR/Cas9 for the treatment of genetic deafness. In addition, important progress in the clinical translation of technologies to treat other forms of hearing loss is expected from a number of prominent companies, such as Decibel Therapeutics, who are currently working on various forms of inner ear therapy and specifically on regeneration strategies.³

ANers interested in keeping up with the progress of gene therapy for combating acoustic neuroma may wish to look at the websites of the biotech companies cited in this report. The founders of the Boston-based biotech named Akouos [‘Listen’] did a ‘Medical Report’ for the Acoustic Neuroma Association about gene therapy research: “Gene Therapy: An Emerging Strategy to Combat Acoustic Neuroma,” ANAUSA Notes, December, 2019). The company hopes to “stabilize or shrink tumor growth using an AAV vector containing the genetic material encoding a protein that functions like [the drug Avastin].” Rescue Hearing Inc (Gainesville, FL) is also researching this approach. The website provides interesting video interviews with the company founder-CEO, Jim Ayala, and team member Dr. Jeff Holt, currently Professor of Neurology at Harvard Medical School. Gene therapy and viral vector technology are explained on the website, and there’s a section comparing genetic, age-related, and noise-induced hearing loss.

³ S.Taiber & K.Avrahan, “Genetic Therapies for Hearing Loss: Accomplishments and Remaining Challenges,” *Neuroscience Letters* (Nov 20, 2019). Free full text copy available at www.PubMed.gov. For the Clinton White House ceremony celebrating the completion of the Human Genome Project, June 26, 2000, see “Genomics and Personalized Medicine,” ANA/NJ Newsletter (Sept 2014). See the April 2015 issue for “CRISPR Technology for Genome-Editing,”

Surgical Treatment of VS: Does Age Matter?

The number of elderly persons in the U.S. diagnosed with acoustic neuroma (VS) is expected to increase significantly as total population grows, life expectancy rates continue to rise, and easy access to MRI diagnostics expands. Median patient age at diagnosis increased from 49.2 years in 1976 to 60 years in 2015. Life expectancy at birth has increased more than 60% since 1900 from about 50 to 80 years. The table below shows the corresponding increase in life expectancy for seniors at age 65 for the period 1980-2020.

Life Expectancy in Years at Age 65: United States, 1980-2015*

Date	White Male	White Female	Black Male	Black Female
1980	14.2	18.4	13.0	16.1
1990	15.2	19.1	13.2	17.2
2000	16.1	19.1	14.1	17.5
2005	17.0	19.7	15.0	18.3
2010	17.8	20.3	15.9	19.3
2015	18.0	20.5	16.4	19.6
2020	18.1	20.6	16.1	19.5

*Tables 15 (2016) and A (2020), National Center for Health Statistics

There are many single-institution medical journal reports comparing surgical outcomes for older and younger acoustic neuroma (VS) patients. The present article provides a sampling of reports available to read (in abstract or sometimes full text) at www.PubMed.gov.

- Researchers at the University of Utah, Clinical Neurosciences Center, asked (2016): “Does age matter?” They reviewed their records for older patients (>65 years) treated for VS, 2000-2012. The average tumor size was 16.5 mm. They found “no significant differences in surgical complications, facial nerve outcome, or hearing preservation rates between older (N=23) and younger (N=220) patients.” They concluded: “Age alone may not be an absolute contraindication to surgical management of VS.” Other factors need to be considered, such as general health, tumor size, surgical approach and preoperative hearing.⁴

- A Mayo Clinic study (2014) compared outcomes for 20 surgery patients 70-86 years old and a matched group of younger adults 25-69 years old. The mean tumor size was approximately 3 cm. Overall, the elderly patients had poorer preoperative physical status and were 13 times more likely to have long-term post-operative imbalance. There were no differences in surgery related complications or facial nerve function. For the elderly patients, there was a high risk of further tumor growth following STR (subtotal removal); six patients required intervention for tumor remnants after STR.⁵

⁴ C.A.Bowers et al, “Surgical Treatment of Vestibular Schwannoma: Does Age Matter?” *World Neurosurgery*, Vol. 96 (December 2016).

⁵ K.VanAbel, M. Carlson et al, “Vestibular Schwannoma Surgery in the Elderly: A Matched Cohort Study,” *Journal of Neurosurgery*, Vol.120 (January 2014).

(Surgical Treatment of VS, Cont.)

- The acoustic neuroma team at the University of California/San Francisco reported (2003) on the effect of age on hearing preservation, facial nerve outcome, and complication rates following surgery. 150 older patients (>60 years) were compared with 55 younger patients (<40 years). The team found that “there is a lower chance of preserving good hearing in older patients . . . [but] age was not associated with a difference in the rate of good facial outcome. There was a trend toward slightly higher rates of cerebrospinal fluid leak in the older patient group. . . [but] no difference in the rate of other complications.” The team also looked specifically at outcomes following middle fossa for an attempt at hearing preservation. Age, they found, was “associated with a lower rate of preservation of good hearing.”⁶

- The University Health Service Consortium compiles a national inpatient discharge database that can be queried for information about VS surgery patients treated at nearly all academic medical centers and hundreds of U.S. hospitals. Researchers at the Medical University of South Carolina, Charleston, used this national UHC database to identify and analyze 3,697 VS surgical cases for a 3-year time span, 2012-2015.⁷

From the Abstract: “Surgical outcomes, such as length of stay (LOS), complications, and mortality, were analyzed on the basis of race, sex, age and comorbidities during the 30-day postoperative period. Results. The overall mortality rate was 0.38%, and the overall complication rate was 5.3%. Advanced age significantly affected intensive care unit LOS, mortality, and complications. Comorbidities, including hypertension, obesity, and depression also significantly increased complication rates. Conclusion. Modern VS surgery has a low mortality rate and a relatively low rate of complications.”

From the Discussion: “Specific information that is key to VS surgery include tumor size, individual institution case volume, surgical approach, facial nerve function, and hearing status are unfortunately not available through this database. . . The study only involved the 30-day postoperative period which precludes long-term data.” • “We found weight loss, a comorbidity associated with advanced age and/or chronic illness, associated with much poorer outcomes.” • “African Americans were found to have a higher complication rate than other races in this study. . . However, a statewide study of general surgical complications in African American patients found it was mostly due to an increased prevalence of comorbidities.” • “As our results and other studies demonstrate, the potential benefits of watching and waiting in the older population must be balanced against the risks of having surgery at advanced age.”

- The University of South Carolina researchers have also used the UHC national database to investigate the extent to which institutions that perform higher volumes of VS surgery (HVHs) have lower complication rates, shorter LOS, and more routine discharges. For outcomes, the focus is on the importance of surgeon experience rather than patient age.⁸

⁶ J.Oghalai, J.Buxbaum, L.Pitts & R.Jackler, “The Effect of Age on Acoustic Neuroma Surgery Outcomes,” *Otology Neurotology*, Vol. 24 (May 2003).

⁷ J.Hatch et al, “National Trends in Vestibular Schwannoma Surgery: Influence of Patient Characteristics on Outcomes,” *Otolaryngol Head Neck Surgery*, Vol.159 (July 2018). Free full text copy.

⁸ J.Hatch et al, “Does Hospital Volume Affect Outcomes in Patients Undergoing Vestibular Schwannoma Surgery,” *OtologyNeurotology*, Vol.39 (April 2018).



ANA/NJ Virtual Support Meeting

Sunday, February 27, 2022

1:00 to 3:00 p.m. EST

TOPIC:

“Caring, Sharing, Networking & Support”



Currently the Acoustic Neuroma Association of New Jersey (ANA/NJ) is limiting its sharing and educational meetings to virtual ‘Zoom’ opportunities. Future meetings may offer a speaker. Please mark your calendars and plan to join our Winter 2022 virtual support meeting.

Care & Share meetings provide a nurturing, non-judgmental environment with individuals who have shared acoustic neuroma experiences and can provide emotional support and encouragement through the stages of the AN journey.

You do not need to be a resident of New Jersey or a particular area in New Jersey or a member of ANA/NJ to participate, but **you do need to register** [registration information below]. Family members, caregivers, friends, and interested persons are welcome to attend as well. Bring your questions and join peers for this interactive opportunity.

In order to receive a confirmation email with detailed instructions to join our Zoom meeting, send an email to Dave Belonger at dbelonger@verizon.net requesting attendance at the February 27th ANA/NJ Care & Share meeting. You will receive a link to the meeting on or about February 18th.

We look forward to welcoming you!





Acoustic Neuroma Association of New Jersey
65 East Young Street
Somerville, NJ 08876-0233

Wilma Ruskin, President
 Princeton, NJ 08536
ananjinc@aol.com

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

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

Jane Huck, ANA/NJ Directory
 Somerville, NJ 08876
janehuck@msn.com

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For membership in ANAUSA:
Acoustic Neuroma Association
 600 Peachtree Pkwy, Suite 108
 Cumming, GA 30041