



**ANA/NJ Newsletter**  
**Vol. XVIII, No. 1, October 2019**

**Acoustic Neuroma Association**  
**of New Jersey**

A Non-Profit Corporation

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## Spring Meeting, Berkeley Heights March 31, 2019

The Spring meeting on March 31, 2019, was held at the Summit Medical Group facility in Berkeley Heights, NJ. Thirteen patients and caregivers, including four board members, attended. The meeting was a memorable, freewheeling discussion of personal experiences with acoustic neuroma. It was a fun meeting with much useful AN-information sharing. Kathy Cecere opened the meeting. Wilma Ruskin began by demonstrating her 'CaptionCall' telephone designed for eligible persons with hearing loss. (See



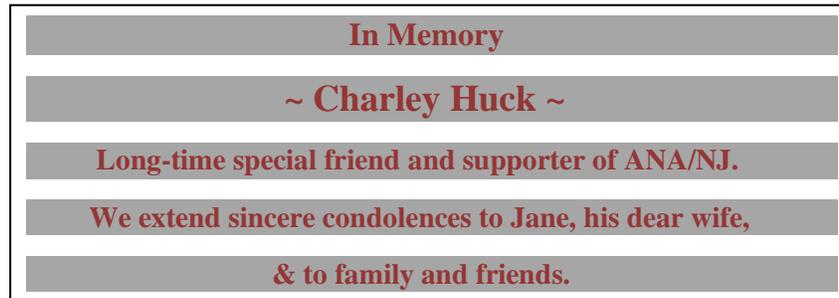
the notice in the ANA/NJ Newsletter for October 2017). 'CaptionCall' is free thanks to the Americans with Disabilities Act. The phone lets you read as well as hear your phone conversations. An Internet connection is needed to get going. For more information, phone 1-877-557-2227 or visit the website [www.captioncall.com](http://www.captioncall.com) on your computer.

This began a lengthy discussion of types of hearing problems and possible solutions, with special attention to bone anchored hearing systems (e.g., the Baha by Cochlear, Ponto by Oticon, Adhear by Bonebridge) designed for patients where traditional hearing aids have proven inadequate and single-sided deafness has likely developed. The Baha bone conduction hearing system, for example, has a titanium bone implant with an external abutment through the skin near the bad ear. A detachable sound processor fits onto the abutment, as demonstrated at the meeting by Naimesh Choksi, who already has the Baha. It was interesting that Clint Sarian, a new member of our support group who is a financial consultant by day and Ninja Warrior by night ([www.smilingninja.com](http://www.smilingninja.com)), expressed personal reservations about Baha because of possible damage to its external audio processor during his Ninja sessions.

There was some confusion about the difference between a bone anchored hearing system like the Baha and a Cochlear Implant (CI). The CI is a much higher level of remediation specifically for individuals who have severe to profound hearing loss in both ears. As advised by the Institute on Deafness of the National Institutes of Health (NIH): "Hearing through a cochlear implant is different from normal hearing and takes time to learn or relearn." (see [www.nidcd.gov](http://www.nidcd.gov)) In our newsletter for Sept 2015, Cindy Rivkin described her experience with the CI. ANers might want to do a Google search for 'What's the Difference between a Cochlear Implant and a Bone Anchored Implant.' Jane Huck observed that for the next ANA/NJ Directory she will be asking patients to report any hearing device they have used.

Dave Lavender described his hearing problems as a professional musician. Special ear plugs have been very beneficial for him. His translab surgery in 2007 for a 3.0 cm acoustic neuroma also led to troublesome balance issues, and he continues to have special physical therapy sessions. Clint Sarian commented on how persistent work with balance helped him to prepare for his unique role as Ninja Warrior.

## Notices



- In July 2018, Kim DeFranco of Marlton underwent Linac radiosurgery for her acoustic neuroma. In May 2019, the PMA Management Corporation’s Mt. Laurel staff donated \$390 to ANA/NJ in honor of their colleague, Kim, and also ‘went gray’ in recognition of National Brain Tumor Month. ANA/NJ is grateful to Kim for sharing her AN story with her colleagues, and thanks her colleagues, in turn, for their generosity and thoughtful support of Kim and ANA/NJ.
- A review of our Directory for July 2016 shows that 13 of the 34 patients listed (38%) chose to manage their small AN with Wait-and-Watch. The median size of the tumors was 8 mm. The largest was 15 mm; the smallest was 3 mm. The 3 mm AN grew by only 6 mm over a period of 12 years; the 15 mm AN grew by only 3 mm in 14 years. Five of the 13 ANs remain under primary observation; six have since had radiation treatment; and two have been treated surgically.
- Dr. James K. Liu (Rutgers/NJ Neurological Institute) has observed:“There’s an increasing popularity amongst neurosurgeons to perform planned subtotal resection of large acoustic neuromas, followed by radiation, in order to preserve facial nerve function. However, not all subtotals are created equal. The larger the subtotal residual volume, the higher the recurrence rate. My philosophy is to always attempt complete removal if safely possible, and make a decision at surgery to perform near total based on intraoperative observations (e.g., adherence to facial nerve), if necessary (*Facebook*, August 19, 2017).
- Waiting for the discovery of a drug to stop the growth of your acoustic neuroma? For an update on progress, check out the informative article “Current and Future Treatment Modalities for Acoustic Schwannomas,” by Drs. Zadeh, Radovanovic and Suppiah (Department of Neurosurgery, University of Toronto), in ANACanada’s newsletter, *The Connection*, Summer 2018. ([www.anac.ca/newsletters](http://www.anac.ca/newsletters)). The article advises that “limited understanding of the molecular drivers of tumor development, in part, is a reason for the dearth of drug development. . . Our laboratory is focused on uncovering the genetic alterations that lead to the growth of acoustic schwannomas.”
- Drs. Samuel H. Selesnick (neurotologist) and Philip E. Steig (neurosurgeon), Weill Cornell Brain & Spine Center, presented an ANAUSA webinar entitled “Important Considerations in the Treatment of Patients with Acoustic Neuroma” (March 25, 2019). Audio-visual and/or transcript of the webinar are available online at the ANAUSA website.

- The Informed Medical Decision Foundation was established in 1989 with the mission to inform and amplify the patient’s voice in healthcare decisions. To learn more, check out the new website at [www.pcpci.org](http://www.pcpci.org).
- Since you’ve asked about tumor size: 2.54 cm = 1 inch. One mm = 0.39 inches. An AN measuring 10 mm (1 cm) in diameter is less than half an inch in size. Still big enough to be a nuisance, to say the least!

### **Tinnitus: “Habituation is a Process”**

“Habituation is a Process” is the apt title for LaGuinn Sherlock’s welcoming letter to readers of the Spring 2018 issue of *Tinnitus Today*, the magazine published by the American Tinnitus Association. This issue of the magazine featured special articles evaluating and recommending habituation for coping with tinnitus. LaGuinn Sherlock is Chair of the Board of Directors of the American Tinnitus Association. She is an audiologist who has worked with thousands of patients toward the goal of habituating to tinnitus. She writes in her open letter to readers: “Until we have cures that silence tinnitus, habituation will remain one of the primary methods to help many patients who suffer from tinnitus. Simply stated, habituation is the reduction in the response to a stimulus after repeated exposure. The idea behind habituation is to work on reducing the reaction to the stimulus sound.”

One of the contributing authors to the issue is Dr. Bruce Hubbard, associate clinical professor at the Icahn School of Medicine and president of the NY City Cognitive Behavioral Therapy Association. His special article is entitled “Navigating the Internet to Promote Habituation.” “My work as a cognitive behavioral therapist,” he writes, “often begins by undoing the damage caused by exposure to inaccurate, negative messaging gleaned from even the most well-meaning tinnitus websites.” For tinnitus patients who “turn to Drs. Google, Yahoo and Bing for help,” he offers the following recommendations:

First, visit websites that are most likely to publish reliable facts about tinnitus and habituation. “Armed with the basics, you will be in a better position to dismiss inaccurate information when you see it.” Dr. Hubbard recommends using the websites of the American Tinnitus Association ([www.ata.org](http://www.ata.org)) and the British Tinnitus Association ([www.tinnitus.org.uk](http://www.tinnitus.org.uk)).

Second, avoid websites, products and people that claim they can make your tinnitus go away. “Habituation is the opposite of trying to make your tinnitus go away. In pursuing habituation you stop trying to change your tinnitus. Instead, you focus your efforts on changing your response to tinnitus by treating tinnitus as an unimportant sound and redirecting your attention and energy to the important stuff in your life. Over time, tinnitus is recategorized by the brain as just another meaningless sound that can be screened out and forgotten.”

Third, if your goal is habituation, find and utilize websites that focus on habituation. Dr. Hubbard’s website is [www.CBTforTinnitus.com](http://www.CBTforTinnitus.com) and he also recommends the expert advice of Dr. Stephen Nagler at [www.Tinn.com](http://www.Tinn.com).

Fourth, on tinnitus forums, seek advice on habituation from people who have achieved it. “Warning signs that a chatroom isn’t serving your best interests include:

- The advice you’re given deviates from the facts you’ve learned from reputable sites.
- The person advising you has been a forum member for years, but continues to struggle with tinnitus.
- You end a session feeling even more discouraged about tinnitus.”

Note: The condition of tinnitus differs between patients. The American Tinnitus Association has prepared a helpful one-page “Patient Navigator” suitable both for those with recent-onset tinnitus and those with a history of tinnitus that has become bothersome and persistent. The **Know Your Treatment Options** section of the Navigator directs attention to the value of consulting the American Academy of Otolaryngology’s *Clinical Practice Guideline: Tinnitus*, available at [www.entnet.org](http://www.entnet.org). The following article offers a brief review of the Guideline.

### “Clinical Practice Guideline: Tinnitus”

This important guideline was published as a 40-page supplement to the October 2014 issue of the medical journal *Otolaryngology – Head and Neck Surgery*, vol. 151. The first author of the guideline and chair of its 23-member development group is Dr. David E. Tunkel, Johns Hopkins Outpatient Center, Baltimore, MD. An abstract of the guideline and a ‘Plain Language Summary’ are provided, and there is an extensive 263-item bibliography of consulted books and articles. A free full-text copy is available at [www.entnet.org](http://www.entnet.org).

As emphasized in the abstract, the focus of the guideline is “tinnitus that is bothersome and persistent (lasting 6 months or longer), often with a negative effect on the patient’s QOL.” The purpose of the guideline “is to provide evidence-based recommendations for clinicians managing patients with tinnitus. . . It will discuss the evaluation of patients with tinnitus, [and] will then focus on the evaluation and treatment of patients with persistent primary tinnitus, with recommendations to guide the evaluation and measurement of the effect of tinnitus and to determine the most appropriate interventions to improve symptoms and quality of life for tinnitus sufferers. . . The target audience for the guideline is any clinician, including non-physicians, involved in managing patients with tinnitus. The target patient population is limited to adults (18 years and older) with primary tinnitus that is persistent and bothersome.”

The main text of the guideline presents evaluations and recommendations for tinnitus in a series of lengthy and well-referenced sections labeled ‘Statements.’ As for example:

Statement 6 stresses the need for education and counseling. “Most patients and many clinicians do not know the options available for management of tinnitus. Patients face tempting advertisements and claims of treatments and cures. Some patients will seek any kind of treatment offer that has the appearance of legitimacy. Clinicians should avoid negative statements such as: *You’ll just have to live with it*. Clinicians should emphasize that there are many things patients can do to make it less of a problem and thereby improve their QOL. No treatment method has been proven to provide long-term suppression of tinnitus, but there are evidence-based interventions to help.”

Statement 7 recommends that patients with some hearing loss should first investigate the beneficial effects of using a hearing aid.

Statement 8 evaluates tinnitus masking therapy (TMT) for promoting habituation to tinnitus -- as for example in TRT (Tinnitus Retraining Therapy) and NTT (Neuromonics Tinnitus Treatment). The guideline finds that evidence is currently lacking that tinnitus can be cured using acoustic stimulation.<sup>1</sup> But “lack of conclusive evidence should not be interpreted as lack of effectiveness.” TMT can provide relief, and clinicians should recommend sound therapy to patients as an option. However, for optimal management: “There may be the need for additional psychological intervention. . . such as CBT/cognitive restructuring techniques.”

Statement 9 strongly supports that CBT should be recommended by clinicians for patients with persistent, bothersome tinnitus.<sup>2</sup> Cognitive Behavioral Therapy focuses on training the brain to replace

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<sup>1</sup> Citing J.Hobson, “Sound Therapy (masking) in the Management of Tinnitus in Adults,” *Cochrane Data-base Syst Rev*, Vol 11 (2012).

<sup>2</sup> Citing P.Martinez-Devesa, “Cognitive Behavioral Therapy for Tinnitus,” *Ibid.*, Vol 10 (2010).

negative thoughts with positive ones to change your reaction to tinnitus. A sample 8-week CBT program is shown in Table 14. Internet-delivered CBT is said to be available.

Statements 10-13 recommend against the use of medications such as antidepressants; dietary supplements such as Ginkgo biloba or zinc; and transcranial magnetic stimulation. Evidence was insufficient to either recommend or discourage using acupuncture for treating tinnitus.

### **Endoscopy: “An Emerging Therapy”**

The October 2018 issue of the newsletter called attention to the CNS/AANS “Evidence-Based Guidelines on the Treatment of Vestibular Schwannomas.” We reported on the guidelines recommended for the categories of Wait-and-Scan, Partial Removals, and Fractionated Radiation.

Another important category investigated for the Guidelines was “Emerging Therapies,” to include endoscopy, the visualization of interior body structures by means of a lighted, flexible fiber-optic instrument called an endoscope.<sup>3</sup> The investigating committee considered endoscopic-assisted surgery for vestibular schwannomas to be “an emerging surgical technique” with “an advancing/evolving technology.” It was also observed that endoscopic surgery “is a skill set that is not necessarily learned quickly; it may be difficult for surgeons in general to adopt the technique.”

The medical literature was reviewed for the Guidelines in search of data in answer to one basic question: “Does endoscopic assistance make a difference in resection [microsurgery] or outcomes in patients with VSs?” Special attention was given to the report published in 2013 by Dr. M. Chovanec comparing outcomes for 44 microsurgery patients (mean tumor size 2.8 cm) with the outcomes for 39 endoscopy-assisted microsurgery patients (mean tumor size 2.6 cm).<sup>4</sup> All surgeries were done via the retrosigmoid approach. Adjunctive use of the endoscope due to its angled optics, magnification and illumination provided a superior view in the operative field. Patients with endoscopic assistance were found to have better facial nerve outcomes, better useful hearing preservation, and lower rates of CSF leaks. In seven cases, the adjunctive use of the endoscope disclosed residual tumor that needed to be removed; in five patients, potential CSF leak formation was identified. Tumor recurrence was not observed during follow-up.

Following the full review of medical journal reports for 1996-2011, the committee concluded, somewhat cautiously: “Endoscopic assistance is a surgical technique that the surgeon may choose to use in order to aid in visualization.”

Dr. Paul Gardner, who specializes in endoscopic surgery at the University of Pittsburgh Medical Center, was pleased to cite this Guideline when presenting his 2018 ANA-USA webinar entitled “Role of the Retrosigmoid Approach and Endoscopy in Hearing Preservation.”<sup>5</sup> Dr. Gardner agreed that special training is needed for endoscopic surgery. Still, for VS patients with small tumors extending beyond the midpoint of the internal auditory canal, he recommended a retrosigmoid approach with improved visualization of the tumor by use of the endoscope. This, he said, would be a beneficial treatment option beyond the more standard middle fossa approach for small tumors. The endoscope could assist in having complete removals of tumor. “I think,” he said, “less than 5% of the time we’ll see a little something that we just didn’t see with a microscope that we’ll then remove with the endoscope. So it’s not an absolute

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<sup>3</sup> See [www.cns.org/guidelines](http://www.cns.org/guidelines): No.9, Guidelines on Emerging Therapies for the Treatment of Patients with Vestibular Schwannomas.

<sup>4</sup> M.Chovanec et al (Dept of Otorhinolaryngology, Charles University, Prague, Czech Republic), “Impact of Video-endoscopy on the Results of Retrosigmoid-transmeatal microsurgery of VS: Prospective Study,” *Eur Arch Otorhinolaryngol*, vol. 270 (4) (March, 2013).

<sup>5</sup> See ANAUSA.org, Webinar Library, June 27, 2018.

game changer, but there is a small percentage of the times when the endoscope will allow us to get a greater amount of removal.”

Dr. Gardner was asked about having an improvement in hearing after endoscopic- assisted surgery. He replied: “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 of hearing after surgery, radiation, any treatment is extremely low.”

## **Wait-and-Scan Management of Patients with Vestibular Schwannoma (VS)**

There’s a valuable review article with discussion of current research on Wait-and-Scan management of VS available online for reading and download at the [PubMed.gov](http://PubMed.gov) website.<sup>6</sup> New VS patients contemplating opting for Wait and Scan management of their tumors may wish to discuss sections of this medical journal article with their treating physicians. There are sections for:

- 1) Introduction: treatment trends
- 2) Biological behavior of VS
- 3.1) Risks & complications of microsurgery
- 3.2) Risks & complications of radiotherapy
- 4.1) Advantages of wait and scan procedure
- 4.2) Reports from different countries
- 4.3) Growth rates of VS; when to intervene; hearing preservation
- 5) Using non-contrast MRI for serial imaging to lower cost and avoid possible complications related to multiple gadolinium-contrast scans.<sup>7</sup>

The abstract for the article states: “There has been an evolution in the management of VS from active treatments (microsurgery and stereotactic radiotherapy) to conservative management (wait and scan). Regular MRI scanning is necessary to monitor tumor progression. Conservative management causes significantly less complications and offers a higher quality of life compared with active treatments. If significant growth occurs, active treatment is considered.”

## **Have You Taken a Look at PubMed.gov?**

PubMed.gov has been called the “true liberator of medical knowledge in the National Library of Medicine.”<sup>8</sup> Virtually all published research articles from the thousands of professionally recognized and peer-reviewed journals are archived on this website in summary form. PubMed comes with a powerful search engine that will quickly identify by topic virtually all research reports. The NLM has zealously pursued the goal of making medical information free, open and easily tapped.

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<sup>6</sup> Jing Zou (Changhai Hospital, Shanghai) & Timo Hirvonen (Helsinki Hospital, Finland), “Wait and Scan Management of Patients with Vestibular Schwannoma and the Relevance of Non-contrast MRI in the Follow-up,” *Journal of Otology*, vol. 12(4) (December 2017). 18 pages plus bibliography. Use the Search engine for the abstract; then, if you wish, click at the top-right for the free full text copy.

<sup>7</sup> See also D.Coelho et al, “MRI Surveillance of VS without Contrast Enhancement,” *Laryngoscope*, vol. 128 (1) (January 2018).

<sup>8</sup> See “PubMed! The True Liberator of Medical Knowledge,” ANA/NJ Newsletter (Sept 2007).



National Library of Medicine  
Bethesda, Maryland

Articles in our newsletter are usually footnoted to encourage you to take a look on your own at the important research reports about acoustic neuroma that are available to you in the medical journals. Simply go online to [www.pubmed.gov](http://www.pubmed.gov) and use the search engine there to call up the abstracts of the reports we have cited. PubMed will also direct your attention to related reports. For some reports, PubMed will provide a link to a free full-text copy. Reading the full text of any research report is always to be preferred. Most times, however, PubMed will only provide links for ordering copies from reprint services (at much too high a price, we think). Better would be to ask the Interlibrary Loan Service at your local library to order a copy of the report you wish to read in full. There may or may not be a small charge.

### *~ Special Notices ~*

#### *Due to unforeseen circumstances . . .*

- The regular Fall meeting, usually held in October, has been postponed. The next meeting of ANA/NJ is scheduled tentatively for **April 19, 2020**. This will be an informal “Care-and-Share” meeting rather than the one-day mini-conference proposed in our March 2019 newsletter. This meeting will be held at the Lawrence Library Mercer County 1 to 4pm.
- Publication of the ANA/NJ Directory had to be put on hold in early May. Plans are to have it ready for publication in January 2020, but we would like to include more people in the new directory. Of particular interest are:
  - people who began their AN experience in the last 5 years or so, as their information on procedures/doctors/treatments, etc. will be more up to date.
  - people who now use a hearing assistive device/hearing aid. This information will be a new addition in our directory and will be of particular interest to those who are considering using an aid or device.

If you did not complete and return the directory form sent to you in April and would like your information to appear in the new directory, please contact Jane Huck at [janehuck@msn.com](mailto:janehuck@msn.com) or 908/725-0233 to receive another 2019-20 directory form.

**\*HELP WANTED\***

The Executive Board is looking for ANA/NJ members and friends who would be willing to share a bit of their time and talent in areas relating to **program planning** for future meetings; and/or **upgrading the ANA/NJ website** to enhance our presence on social media; and/or improving our **outreach to contacts on Facebook**.

To offer to help, provide input, or have questions answered,  
feel free to call Wilma Ruskin at 609-510-9039.

