



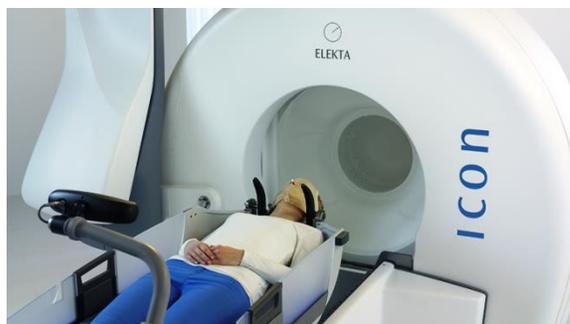
**ANA/NJ Newsletter
Vol. XV, No. 4, March 2017**

**Chapter Meeting, Lawrenceville
October 23, 2016**

Our Fall meeting was held at the Mercer County Library in Lawrenceville (Route 1 South). Twenty-two people attended for an open discussion of acoustic neuroma experiences, either past or in progress. Dave Belonger, vice president of ANA/NJ moderated the meeting and introduced the other members of our board who were present. Copies of a newsletter article, “ANA Patient Survey, 2014,” were distributed to show how patients have been handling acoustic neuroma (AN).

Dave asked each of the new patients at the meeting to speak briefly about their own experiences to date. To summarize: One patient who had Gamma Knife treatment for a 1.4cm tumor spoke in praise of the Phonak CROS wireless hearing aid for coping with his single-sided hearing loss. Four patients all with small tumors (5mm, 1.2cm, 1.3cm, 1.9cm) reported that they were currently Wait-and-Watch. Some hearing loss was the common symptom in these cases, and radiation treatment appeared to be the favored eventual treatment, if needed. Another patient was uncertain about her tumor size (given as 2.1, 1.0, 1.0); it was suggested this had to do with her tumor’s irregular shape and that she might ask to see a copy of her MRI showing the tumor. One patient whose 2.9cm tumor was treated surgically reported on his continuing serious post-op problems involving balance and fatigue. He described the vestibular-visual therapy he has been undergoing. Another patient with a 2.9cm tumor described how he was contemplating having treatment by either surgery or Gamma Knife radiosurgery. Discussions among patients about these AN experiences continued after the meeting was adjourned.

New Gamma Knife System



The Elekta company has introduced *Icon*, its newest, sixth generation model Gamma Knife brain radiosurgery system. The new system will provide innovation in speed of radiation treatment, precision and patient comfort. Most noteworthy for acoustic neuroma patients, *Icon* opens up the possibility of

treating tumors close to the cochlea or other critical brain regions with multiple sessions of radiation without use of the stereotactic frame. There is real-time motion management. The company states: “With Icon, a similar level of precision can be achieved with frameless immobilization as with the frame. The high definition motion management system monitors the patient in real time during treatment with 0.15mm accuracy, six times better than industry standard. If the patient moves outside of the pre-set threshold, the system’s gating functionality instantly blocks the radiation.” Among the first medical centers to install *Icon*, probably by early 2016, are the University of Pittsburgh, the University of Virginia, and MD Anderson at the University of Texas. For further information and a video about Gamma Knife *Icon*, visit the website www.careforthebrain.com.)

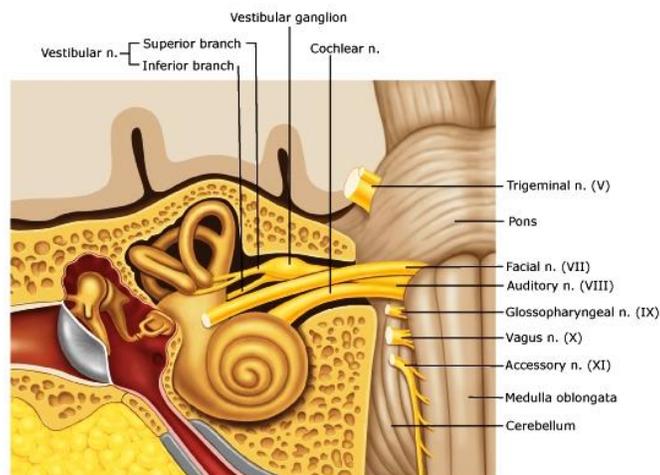
Notices

- Looking ahead, ANA/NJ and leaders of the NYC Support Group have begun talking about organizing a joint NJ-NY Mini-Conference for acoustic neuroma. The conference would be held in New Jersey sometime during the spring of 2018. We’ll keep you informed.
- The ANA website (www.ANAUSA.org) provides a *Support Group Meeting Video Library* (click on ‘Finding Support’) open to both members and non-members. Two excellent videos currently in this file are: “The Vestibular System and How it is Affected by Acoustic Neuroma,” by Dr. Laura Wazen, DPT, Equinox Physical Therapy (November 7, 2015); and “Radiosurgery Explained,” by Dr. Mary Ellen Masterson, chief physicist, Tampa Bay Gamma Knife Center (April 30, 2016).
- For help finding hearing professionals near you, the website www.Healthyhearing.com provides an easy-to-use Directory of Consumer-Reviewed Professionals.
- Wilma Ruskin has called attention to the website [www. Hear-It.org](http://www.Hear-It.org)., which is good for information and news about hearing, hearing loss, hearing aids, and tinnitus, among other topics. There’s a link to the site’s videos on YouTube.
- The magazine *Science*, vol.354 (11 Nov 2016), has an up-date entitled “For Chronic Fatigue Syndrome, a ‘Shifting Tide’ at NIH,” reporting that the National Institutes of Health (Francis Collins, director) has increased research funding for what is now being called CFS/ME, Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. For acoustic neuroma patients concerned about experiences with long-term fatigue, the ANA/NJ Newsletter discussed this malady in the issues for June 2004, January 2005 and September 2008. The November 2016 article in *Science* concluded: “After decades of frustration, the mysterious disease remains maddeningly elusive.”

Cutting the Balance Nerve

Why is the balance (vestibular) nerve cut during surgery for acoustic neuroma? Dr. Edward Cho, a staff otolaryngologist at the House Clinic in Los Angeles, was asked this candid question during the Q&A for his ANA Webinar dealing with “Balance Problems after Acoustic Neuroma Surgery” (September 18, 2015). He was temporarily taken aback by the question and responded that the ‘why’ of it was really in the province of surgeons to explain. He didn’t know. But he believed there was a theory that if some balance nerve fibers are left during surgery they can sometimes misfire afterwards resulting in post-op dizziness problems for the patient. He said he didn’t know of any published studies about this.

Actually, Dr. Cho had spoken earlier in his presentation about how cutting the vestibular nerve during translabyrinthine surgery had the benefit of avoiding any abnormal balance signals being sent to the brain after treatment. He was on the right track with this. Researchers at Leiden University Medical Center in the Netherlands, for example, have reported on how acoustic neuroma patients presenting with disabling vertigo have had their quality of life significantly improved by translabyrinthine tumor removal; and a study at the International Neuroscience Institute in Hanover, Germany, concluded that retrosigmoid surgery was safe and very effective in providing relief for patients with disabling vestibular dysfunction, including vertigo.¹



Cutting the vestibular nerve is in fact routine in acoustic neuroma surgery regardless of the presenting symptoms of the patient or the surgical approach employed. “When an acoustic neuroma is removed by microsurgery, the balance fibers in which the tumor is growing are removed along with the tumor.”² They have been compromised by the tumor and are for the most part either non-functioning or close to it. Cutting the nerve avoids any subsequent intermittent malfunctioning of damaged fibers. Of course, the result of cutting is an abrupt loss of balance input to the brain from the affected side. However, it’s done in the knowledge that our amazing brain will soon be able to compensate for the loss. Some visual-vestibular balance therapy will help.

Since you ask: yes, things are different with radiation treatment. There is of course no cutting. Change in balance function does not occur as quickly as with microsurgery. “With radiation, change occurs more

¹ See W.P.Godefroy et al, “Translabyrinthine Surgery for Disabling Vertigo in Vestibular Schwannoma Patients,” *Clin Otolaryngol*, vol 32 (June 2007); and M.Samii et al, “Efficacy of Microsurgical Tumor Removal for Treatment of Patients with Intra-canicular Vestibular Schwannoma Presenting with Disabling Vestibular Symptoms,” *Jour Neurosurg*, vol 17 (June 2016).

² *Improving Balance Following Treatment for Acoustic Neuroma* (ANA Booklet, April 2004), p.5.

slowly, often with some persistence of balance function on the treated side.”³ There is a potential for unsteadiness over a longer period of time.

Cutting the Hearing Nerve

Cutting the hearing nerve is definitely avoided during surgery for acoustic neuroma since it would result in complete loss of hearing in the affected ear of the patient. Thus, doing as little damage as possible to this vital nerve is a main objective when the retrosigmoid and middle fossa approaches for surgery are used, or when low radiation dosages and fractionation protocols for radiation treatments are employed. The notable exception to this strict avoidance of injury to the hearing nerve is the translabyrinthine surgical approach, which totally sacrifices the hearing and balance mechanism of the inner ear. The result for the patient is single-sided deafness. How can this be explained?

The simple explanation is that translabyrinthine microsurgery (TLM), as developed and refined by surgeons at the House Clinic in Los Angeles, is reserved for the treatment of large tumors where the preservation of hearing is not an issue, such as when all serviceable hearing in the affected ear has already been lost preoperatively. Without needing to worry about injury to the hearing/balance mechanism, the surgeon can proceed more readily to expose the tumor. Here’s the description of the approach provided on the House Clinic’s public website (www.acousticneuroma.org):

The translabyrinthine approach involves an incision that is made behind the ear. The mastoid bone and the balance canal structures of the inner ear are removed in order to expose the tumor. This approach results in complete removal of the tumor in nearly every case. One of the main advantages in this approach is that there is little or no retraction of the brain required to provide excellent exposure of the tumor. Another advantage is early and direct localization of the facial nerve which facilitates separation of the nerve from tumor, optimizing facial nerve outcome. After completion of tumor removal, the opening in the mastoid bone is closed with a fat graft which is taken from the abdomen.

This approach sacrifices the hearing and balance mechanism of the inner ear. As a consequence the ear is made permanently deaf. Although the balance mechanism is removed on the operated ear, the balance mechanism in the opposite ear provides stabilization for the patient.

The benefit of cutting the balance nerve for patients with vertigo is noted on p.3 of this newsletter. Could cutting the hearing nerve have any benefit as a surgical intervention for tinnitus? As early as 1981, Drs. John W. House and Derald Brackmann at the House Clinic looked at 414 cases of surgical removal of acoustic tumors with excision of the hearing nerve. They found that only 40% of the patients overall had improvement in their tinnitus. For the 68 patients who had TLM, improvement in the tinnitus occurred in 45%, while 55% reported the condition to be the same or worse. Their report concluded: “Surgical management of tinnitus, although successful in some cases, does not provide a valid and reliable mode of treatment for subjective tinnitus.”⁴

A recent report from Yonsei University in Seoul, Korea (2014) evaluated changes in tinnitus in 46 patients after either TLM or Gamma Knife radiosurgery (GKS). In the TLM group (n=27), there was a higher rate of tinnitus improvement (52%) than in the GKS (16%). The rates for tinnitus worsening were TLM (11%) and GKS (74%). The report concluded: “In cases where hearing preservation is not intended, microsurgery with vestibulocochlear neurectomy (cutting the balance and hearing nerves) during tumor removal can sometimes relieve or prevent tinnitus.”⁵

³ Ibid., p.7.

⁴ “Tinnitus: Surgical Treatment,” *Ciba Foundation Symposium*, 85 (1981).

⁵ “Change in Tinnitus after Treatment of Vestibular Schwannoma,” *Yonsei Med Journal*, 55 (Jan 2014).

Getting the Right Diagnosis

Owen Tripp is the cofounder and CEO of Grand Rounds, a San Francisco healthtech company established “. . . to help people find a physician who will give them the right diagnosis the first time around and link patients with experts who can give second opinions.” ANers will be curious to ask: what would a man in Owen Tripp’s position do after he woke up one morning (as happened in the spring of 2016) to find that he couldn’t hear anything in his right ear? What actions would he take? Was he able to get the right diagnosis of his hearing problem?

Science writer Matthew Herper interviewed Owen Tripp and wrote about his experience for an article in *Forbes* entitled “Refer Madness: Should Big Data Pick Your Next Doctor?” (December 30, 2016). In the interview, Tripp told Herper that he met first with his doctor, who said that the right ear was just ‘clogged.’ He also recommended an ENT – an ear, nose and throat specialist – for a second opinion. Tripp went on the Internet to look at the web page of the ENT. He remembers that he was troubled to find that her expertise was in swallowing, not hearing. Herper comments at this point that most people would have gone to see the ENT anyway. But Tripp was CEO of Grand Rounds, a company with a database of some 700,000 physicians, 96% of the U.S. total. Rather than consult with the ENT his doctor recommended, Tripp turned to his staff at Grand Rounds, who used the company’s database to match his hearing disorder with the expertise of a hearing specialist in San Francisco. This doctor prescribed the MRI that resulted in the right diagnosis of Tripp’s hearing problem – namely, a 2.6 cm acoustic neuroma.

So things worked out well enough for Owen Tripp. He got the right diagnosis of his AN, and in a timely fashion. His own doctor’s initial diagnosis of a plugged ear was not unusual; how many times have we heard stories of AN patients whose hearing loss was attributed at first to earwax buildup, or maybe just ‘old ears?’⁶ Tripp’s complaint of hearing loss by itself would not have red flagged the possibility of a brain tumor and the need for an MRI. Besides, the doctor did recommend an ENT for a second opinion. Herper questions Tripp’s decision not to consult with this ENT. But Tripp wanted his second opinion only by someone with special expertise in hearing disorders. This is what his company, Grand Rounds, was all about: the right diagnosis by the right doctor.

Of course, this is the story of an individual in a unique position with special knowledge. How many other individuals with hearing loss would think to contact Grand Rounds for assistance?⁷ Moreover, at Grand Rounds: “For individuals, it costs \$600 to get a doctor recommendation and \$7,500 to get a second opinion.” Actually, although individuals can pay for Grand Rounds, most of its customers get its services through their employers – large companies such as Costco that are reducing their healthcare insurance costs by helping employees find the right doctors and thereby avoid wasteful cases of misdiagnosis and mistreatment. Herper writes that Owen Tripp is “particularly proud that Grand Rounds is offering blue-collar workers the kind of medical care once available only to the rich.”

Grand Rounds followed up with Tripp’s case by identifying the surgical team at Stanford University that eventually removed his tumor. He lost the hearing in his right ear, but his facial nerve was preserved. It should be noted that Stanford’s Chief of Interventional Radiology, Dr. Lawrence “Rusty” Hofmann, was the co-founder of Grand Rounds with Tripp in 2012.

⁶ For recently reported stories to think about, see “A Tale of Two Acoustic Neuromas,” in *ANA Notes* (December, 2016).

⁷ Or a competing company such as Best Doctors, 2ndMD, Doctor on Demand, Teledoc or Accolade?

Gifts & Donations to ANA/NJ

January 1, 2015 – December 31, 2016

The Executive Board of ANA/NJ gratefully acknowledges those who have contributed to ANA/NJ in support of its mission to provide information, encouragement and support to acoustic neuroma patients and their families.

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Chapter Meeting - Spring 2017

“Acupuncture, Meditation, Stress Management & More: The Benefits of Integrative Medicine Approaches for AN Patients”



Patricia A. Graham, MD

Dr. Graham is a Psychiatrist and Acupuncturist on staff at the Princeton Medical Center. She is Board Certified in Physical Medicine and Rehabilitation

Sunday, March 26, 2017

1:30 – 4:00 pm

University Medical Center of Princeton at Plainsboro

The Education Center

One Plainsboro Road, Plainsboro, NJ 08536

Refreshments Social Time

Directions

The University Medical Center of Princeton is located just off the northbound side of Route 1, between Plainsboro Road and Scudders Mill Road. (Visit www.princetonhcs.org)

- **Going north on Route 1**, right turn onto Plainsboro Rd, and then take the jughandle at the traffic signal to make a left onto **Punia Blvd**. Stay for a short distance on Punia Blvd until the sign for **Parking Lot V2**. Turn left and park in **Lot V2**.

(**Notice:** The main entrance to the hospital with its large glass windows will be seen on your left, but park by the low brick hospital wing and grassy area that stretches to the right. A direct entrance to the Education Center will be at the end of the walkway there. Look for the ANA/NJ sign!)

- **Going south on Route 1**, take the overpass over Rt 1 for Scudders Mill Rd. Bear right onto Campus Rd and go to the traffic signal. Turn right onto Hospital Dr and then quick left onto Punia Blvd to the sign for Parking **Lot V2**. See the above notice for the direct entrance to the Education Center.

