

ANA/NJ Newsletter
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**Chapter Meeting, Berkeley Heights,
April 10, 2011**

Our speaker was Dr. Samuel Selesnick of the Center for Skull Base Surgery, Weill Cornell Medical Center, New York Presbyterian Hospital. Dr Selesnick presided over “An Open Discussion: Everything You Ever Wanted to Know about Acoustic Neuroma.” Thirty people attended the meeting.



Dr. Selesnick began by observing how things have changed greatly since he began his practice twenty years ago. For example, acoustic neuroma patients are no longer routinely scheduled for surgery; tumor localization has improved because of better imaging; new types of radiation therapy have been developed; surgery approaches have improved; post-treatment rehab is much better, including new devices for loss of hearing.

In response to a wide range of questions, Dr. Selesnick made the following observations:

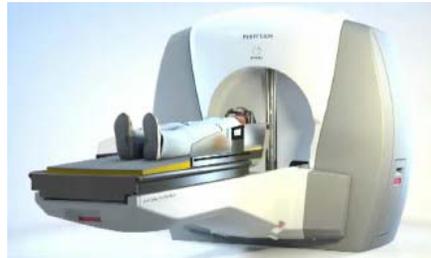
- Gamma Knife treatment for a tumor regrowth seven years after surgery should be a safe and effective way to go.
- Measuring tumor size by volume is better than by diameter, but volume is simply not used, mainly because of computer software issues.
- Regarding the reason for treating a small tumor with no bothersome symptoms, the fact is that there is no good correlation between tumor size and symptomatology. For example, serial imaging may not show tumor growth and yet hearing loss can increase.
- Saving hearing remains a problem for treatments for acoustic neuroma. With radiation treatments, hearing may deteriorate over a period of time, whereas with surgery you will know right away. Fortunately there are excellent devices today for coping with hearing loss.
- Tumor regrowth after two surgeries would be very unusual.
- At present, there is no cure for tinnitus.
- Radiosurgery is single-session radiation treatment, either by Gamma Knife or Linac, whereas radiotherapy is multiple-session treatment by Linac (or possibly by proton beam). Dr. Selesnick questioned the value of multiple sessions and stated his preference for radiosurgery.
- Regarding postop facial nerve problems, these are usually transient with acceptable recovery over time. In general, the longer it takes the poorer the recovery.

Following Dr. Selesnick’s presentation, there was much discussion among attendees. Refreshments were available.

Notices

- The new Gamma Knife Center at Robert Wood Johnson University Hospital in New Brunswick offers treatment for acoustic neuroma using *Perfection*, the latest Leksell gamma knife stereotactic radiosurgery system. The *Perfection* (192 Cobalt-60 Source) provides increased patient comfort and reduced treatment times. As described by the manufacturer (Elekta), the system is robotic for patient positioning, dose planning is fully automated, and its unique collimator ensures superior accuracy and

reduced residual dose to unintended areas. For more information, go to www.rwjuh.edu/gamma-knife and www.elekta.com. See Gamma Knife article, below.

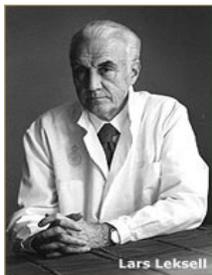


Gamma Knife Perfection

- At the June 2011 ANA Symposium in Cincinnati, Dr. Richard Wiet (University of Chicago Ear Institute) reported that the origin of tinnitus is still unclear and that there is still no definite cure. However, a significant “breakthrough” emphasized by Dr Wiet is the research finding that tinnitus is “the result of a neurological change in the auditory system and adjacent parts of the brain.” New-type brain imaging studies fusing functional MRI with SPECT (single proton emission tomography) have shown that several areas of the brain are involved, not just the auditory cortex. In other words, things are getting more challenging, and promising, as researchers find parts of the brain previously not known to be involved in tinnitus generation. Better understanding of this complexity should facilitate the development of drug therapies. Meantime, Dr Wiet’s advice for tinnitus sufferers is to “hold on.” New treatments will be coming along.
- You are invited to check out ANA/NJ on “**Facebook.**” Just look for the ANA/NJ group at www.facebook.com. You can post a comment, ask a question, exchange information, connect with ANA friends. Take a look!

Introducing New Ideas in Medicine: Stereotactic Radiosurgery

The Gamma Knife *Perfection* is the newest version of the stereotactic radiosurgery machine conceived of by Dr. Lars Leksell for noninvasive treatment of brain tumors and brain disorders. Leksell (1907-86), a



noted neurosurgeon at the Karolinska Institute in Stockholm, Sweden, presented the defining scientific paper on “The Stereotaxic Method and Radiosurgery of the Brain” sixty years ago in 1951. He defined stereotactic radiosurgery as “the destruction of intracranial targets without opening the skull using single high doses of ionizing radiation in stereotactically directed narrow beams.” One of his close associates at the time, Dr. Ladislau Steiner, has recorded how Leksell deliberately used the term radiosurgery to stress that the procedure had little to do with the conventional x-ray therapy of the day with its approximate fields of radiation and multiple-session low dose procedure. The new idea was for precise target localization and single-session treatment employing a high radiation dose. Steiner was correct to observe in his 1985 report on “Radiosurgery in Cerebral Arteriovenous Malformations” that Leksell owed much to previous decades of research on conventional x-ray therapy. Still, Leksell is rightfully called “the father of radiosurgery.”

Having formulated the idea of radiosurgery, the next, critical step for Leksell was to design a practical tool for its clinical application. Earlier in 1949 he had invented the Leksell Stereotactic System for use with open brain surgery. He collaborated now with radiobiologist Dr. Börge Larsson of the Gustav Werner Institute (Uppsala) to adapt this system and its basic principles for closed intracranial radiosurgical procedures. The two researchers experimented initially with proton beam and linear accelerator, but selected finally Cobalt-60 as their radiation source (gamma rays). Leksell was the driving force of the team. He pushed forward confidently, and stubbornly, with “considerable private funding,” and in spite of opposition from the neurological establishment, until a prototype gamma unit (179 Cobalt-60 Source) was finally in place at the Karolinska Institute in 1968. This critical invention, we note, from idea to clinical tool, took approximately 17 years, 1951-68.

This was the first “Gamma Knife,” so-named to highlight the precise ‘scalpel-like’ radiation dose the gamma unit would deliver. The new tool was designed for functional brain disorders such as Parkinson’s disease, severe pain and epilepsy, although it was actually used in 1969 to treat a patient with acoustic neuroma. In fact, attention soon turned to radiosurgical treatment of brain tumors such as acoustic neuromas and vascular malformations such as AVMS. For this purpose a second, redesigned gamma unit was built in 1975; the older unit was donated in 1981 to the University of California at Los Angeles for research. The new model Gamma Knife (201 Cobalt-60 Source) began to be used extensively at the Karolinska Institute, and gamma units three and four of this same model went into operation by the early 1980s in Sheffield, England, and at the Centro de Neurocirurgia in Buenos Aires, Argentina. And Gamma Knife No.5 (the fifth in the world) would go to the Presbyterian-University Hospital, University of Pittsburgh Medical Center, Pittsburgh, PA, where it became operational on August 14, 1987.



Bringing Gamma Knife technology to the U.S. was the achievement of Dr. L. Dade Lunsford, who is currently the Lars Leksell Professor of Neurological Surgery and Director of the Center for Image-Guided Neurosurgery at Pittsburgh. Dr. Lunsford did his residency in neurological surgery at Pittsburgh, 1975-80, and became a member of Dr. Peter Jannetta’s Department of Neurological Surgery in 1980. He flourished in the “environment of creativity” fostered by Jannetta, and was awarded the AANS Van Wagenen Fellowship for 1980-81 for study in stereotactic radiosurgery with Professors Leksell and Erik-Olof Backlund at the Karolinska Institute. As he described later in his report on the first U.S. Gamma Knife (*Neurosurgery*, Vol. 24, 1989), “the strategy to import a gamma unit began in 1982.” It was a daunting affair, a six-year effort of sometimes frustrating negotiations with local institutional committees and state and federal bureaucratic agencies. “The regulatory agency review process for this new technology was formidable. The multi-stage review by the NRC [Nuclear Regulatory Commission] took almost 3½ years.”

The arrival of Gamma Knife at Pittsburgh did not signify that the new technology had now “caught on” and was immediately accepted in the U.S. as an approved option for treating acoustic neuroma. Lunsford’s achievement was visionary rather than in response to an urgent demand. Even abroad, 19 years after the first gamma unit was installed at the Karolinska, only about 200 acoustic neuroma patients had been treated by radiosurgery, while in the U.S. radiosurgery was still largely unknown even among neurosurgeons. Dr. Steiner observed that “for the overwhelming number of neurosurgeons, radiosurgery [was] still a fairly exotic topic.” Acoustic neuroma patients in the U.S. during the 1980s were routinely scheduled for microsurgical removal of their tumors. The prevailing medical establishment view was pronounced most succinctly at the NIH Consensus Development Conference on Acoustic Neuroma in 1991: “Radiation therapy is a treatment option limited in current practice primarily to patients unable or unwilling to undergo otherwise indicated surgery.” The Conference asked for more data and long-term studies to assess fully the efficacy of radiation treatment for acoustic neuroma.

Lunsford was the key speaker for radiosurgery at the NIH conference, and it's noteworthy that the conference findings reflected views he had already expressed in his 1990 report on "Radiosurgery for Acoustic Neuroma: Early Experience" (*Neurosurgery*, vol 26, 1990). That report stated: (1) that it was unlikely that radiosurgery using the gamma knife would supplant microsurgical removal as the best treatment for acoustic neuroma; (2) that it was an alternative treatment for patients who were elderly or medically infirm or who refused surgical intervention; (3) that "critical minimal and maximally effective radiosurgical doses have not been precisely defined"; (3) that outcome issues with facial weakness and trigeminal nerve damage needed to be addressed; and (4) that long-term studies were needed for data on hearing loss and tumor regrowths. All of which will remind us that gamma knife radiosurgery did not arrive in the U.S. in 1987 complete with all the accumulated 20-year experience, knowledge, research-based advances and technological refinements associated today with the 2007 gamma knife unit called *Perfection*. It's difficult actually to read about the first years of Gamma Knife in the U.S. without realizing how very experimental radiosurgery still was at the time. Lunsford was a pioneer in the field of radiosurgery. This was why he was honored in 2007 by the Congress of Neurological Surgeons.

Lunsford led the way for the establishment of Gamma Knife centers in the U.S. Pittsburgh was first in 1987; Virginia, Chicago, Dallas and Atlanta came next in 1989. Today there are about 110 centers in the U.S. and over 300 worldwide. But Lunsford's larger achievement has been to establish and maintain Pittsburgh as a model "Center of Excellence" for gamma knife radiosurgery in terms of high professional standards, clinical research, resident training and public education. In no small way, what has advanced the success and status of radiosurgery (and radiotherapy) over the years has been Lunsford's steady "commitment to rigid outcomes evaluations, publication (in books and 431 articles) and presentation of results (at national and international meetings) and education." Pittsburgh is justified in the claim that "The modern era of acoustic tumor radiosurgery was ushered in under Dr. L.Dade Lunsford." (See "Future Perspectives in Acoustic Neuroma Management," December 19, 2007, at www.acousticneuromaneurosurgery.pitt.edu)

Some Thoughts about "Medical Tourism" and Acoustic Neuroma

Medical Tourism, according to the Medical Tourism Association, an international organization for promoting healthcare to patients in a global environment, "is where people who live in one country travel to another country to receive medical, dental and surgical care while at the same time receiving equal or greater care than they would in their own country, and are traveling for medical care because of afford-ability, better access to care or a higher level of quality of care." Notice in this long definition that there is no mention of combining tourist activities with healthcare. It sounds more like Medical Travel than Medical Tourism. One health travel company for hospitals in India, We Care Health Services, in fact cautions its international clients: "The tourism part of the process is viewed as the least important factor and should only be considered once you are fully recovered." (www.Indiahealthtour.com) Josef Woodman, in his 'must read' book on medical travel, *Patients Beyond Borders: Everybody's Guide to Affordable, World-Class Medical Tourism* (2008), warns against the media image of "devil-may-care patients jet setting overseas for treatment, then heading to exotic resorts for two-week romps." Woodman's research showed that for the overwhelming majority of health travelers, "vacation and leisure time [play] second fiddle." He writes: "The single biggest reason Americans travel to other countries for medical treatment is the opportunity to save money." A major caveat by Woodman will already be familiar to AN patients: "Treatment by a medical team with extensive experience is critical to your best chances for a successful outcome. For big surgeries, you should head

to the big hospitals that have performed large numbers of exactly your kind of procedure.” He cautions also that any scheduled pre-treatment vacation-time can easily be spoiled by constant fretting over an impending medical procedure. And he emphasizes that health travelers also need to make allowance for post-treatment discomforts or complications. In this regard, we thought for example of the nine months of post-op problems after acoustic neuroma surgery in California that Shari Bookstaff describes in her recent “Voyages” essay for *ANA Notes* (September 2010). Her serious breathing and swallowing difficulties called for two additional surgeries and a long period of specialized rehabilitation. Coping with all this would certainly have been extra hard in a foreign country away from family and friends. Shari writes that even in her rehab facility in Marin County, CA, “I was really cut off from all the people in my life.”

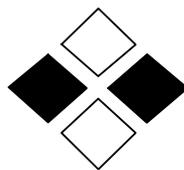
We learned of a special case of medical travel for acoustic neuroma that clearly involved no vacation-time incentives. This is the case reported on by Shiva in her series of emails for the ANA Discussion Forum (April-May 2008). While on a visit in Maryland, Shiva’s beloved Indian mother (age 65) was diagnosed with a 2.2 cm acoustic neuroma and was advised by a doctor that she should have Translab surgery. Gamma Knife radiosurgery as a second option was discounted on grounds that a failed radiation treatment would make any subsequent surgery more difficult. Shiva asked the ANA Forum for help. Forum participants recommended getting a second opinion, and Shiva was encouraged also to check the internet for sites such as www.IndianConsultancy.com for treatment centers in India that would charge less than the \$100,000 quoted as about average for surgery in the USA. Cost was a big factor in this case since there was no medical insurance. Shiva used her computer and found the JCI-accredited Apollo Hospital in Chennai (formerly Madras) which quoted \$3,700 for Gamma Knife treatment, to include all lab tests, imaging, fees for neuro-radiologists, neurosurgeon, physicist, nursing, medicines, two-day hospital stay with attendant. Shiva remained uncertain about Gamma Knife, but she decided definitely on India for her mother’s treatment. Besides lower cost, there would be family and friends in India to help care for her mother. On May 29, 2008, mother and daughter flew to Chennai, had a frightening emergency landing at the airport, and met with doctors at the hospital who were found to be still debating treatment options. But finally a decision was made: it would be Gamma Knife, June 4. Some twenty months later, Shiva wrote to update her friends at the ANA Discussion Forum -- her mother’s treatment was successful and doctors say that she “is doing absolutely fantastic.”

Woodman’s guide devotes six pages to the Apollo Hospital in Chennai, “one of India’s most important medical centers, . . . best-known for its orthopedic and cardiology super-specialties.” A total hip replacement is listed at \$7,850; a coronary artery bypass graft at \$7,300. Acoustic neuroma, as might be expected, is not included on this list of “Typical Treatments & Costs,” and for that matter, there is no mention of acoustic neuroma anywhere in Woodman’s guide or on any of the health travel websites we consulted. Shiva used the computer to contact the Apollo Hospital directly to inquire about AN treatment, doctors and costs. For most health travelers, Woodman recommends using a health travel agent -- also called a medical travel facilitator. He writes: “Once you’ve settled on your health travel destination, it pays to seek out the services of that locale’s best health travel agent. Agents usually pay for themselves and are well worth the relatively modest additional fees they typically charge.” The biggest company for health travel in India is The Taj Medical Group, with offices in NYC and extensive physician contacts in India. Woodman’s book also lists PlanetHospital, a US-based company in southern California (www.planethospital.com). For acoustic neuroma, this company currently offers assistance with treatments available in Singapore and S.Korea. Rudy Rupack, the president of PlanetHospital, wrote in response to our inquiry: “The Singapore offices treat [acoustic neuroma] surgically for the cost of approximately \$38,000-\$56,000 depending on the size of the tumor, whereas the S.Korean doctors use proton beam therapy to radiate and destroy the tumor at a cost of \$54,000 including travel (air and

accommodation) from US or Canada for two persons. Some insurance plans (and self-funded plans) are willing to pay for the treatment as well.” Costs for medical procedures in other nations have been running 20 to 50 percent less than those in the USA. Besides Singapore, S.Korea and India, popular destinations have been Thailand, Mexico and Costa Rica. Medical travel by Americans has been mainly for cardiovascular, cosmetic, dental or orthopedic care. We know of no New Jersey acoustic neuroma patients who have opted to travel outside the USA for treatment. New Jerseyans do make the long trip to California for treatment. Our Registry lists 12 patients who had their surgery at the House Ear Clinic in Los Angeles, 2000-2009. In these cases, high quality of care rather than low cost appears to have been the main motivating factor. Of course, strictly speaking, NJ to CA would have to be classified as domestic travel rather than medical travel/or medical tourism.

A report by Philip Moeller posted for the blog *USnews.com* (Feb. 12, 2010) discusses “Growing Reasons to Consider Medical Tourism.” Moeller explains that the new industry has now matured to the extent that medical travel is more accepted and much easier to arrange. Health travel companies have built up their networks of reputable hospitals and physicians. Leading medical schools such as Johns Hopkins and Harvard have established international healthcare referral systems. The major US-provider of foreign hospital certification, the Joint Commission International (JCI), now lists over 200 certified facilities in more than 30 countries. And international conferences, exhibitions and other information exchanges have proliferated. For an appreciation of the globalization of healthcare that is taking place, one needs only to look at websites such as www.MedicalTravelToday.com.

Moeller notes that economic recession in the US caused the number of people traveling overseas for healthcare to decline from 750,000 in 2007 to 540,000 in 2008. The forecast is for a rebound to 1.3 million in 2011, although the consequences of the recent healthcare reform in the US are still unclear. Some anticipate that greater medical insurance coverage for Americans will mean less travel abroad for care. On the other hand, the additional burden the reform package will place on the healthcare system in the US may act to increase waiting times and limit services for patients to the extent that medical travel will increase. US insurance companies may begin to expand medical travel options for American patients. (For the debate, see www.Asiatimes.com)



Fall 2011 Meeting

“A Time to Share”

An Open Meeting for Patients, Family & Friends

October 23, 2011, 1-4 PM

Summit Medical Group
Lawrence Pavilion, One Diamond Hill Road
Berkeley Heights, NJ

Refreshments

Social Time

Directions to Summit Medical Group, Berkeley Heights, NJ

The most direct way to Summit Medical Group is via Route 78.

From **Route 78 East**, take Exit 43 (Berkeley Heights/Watchung). Follow the exit road to the light at **Valley Road** and turn left onto Valley Road. Take Valley Road to the next **light** and turn left onto **Diamond Hill Road**. Follow Diamond Hill Rd to the light at **Mountain Avenue**. Go left on Mountain Ave for a short distance to the entrance to Summit Medical Group on the left. You will see Lawrence Pavilion and parking straight ahead as you enter. In the Lawrence Pavilion lobby, take the elevator down to 1R, the Cafe/Conference area (Note: there is another entrance to Summit Medical Group on the left just before the Mountain Avenue light. Follow the signs for Lawrence Pavilion/Parking Lots 1&2.

From **Route 78 West**, take Exit 43 (New Providence/Berkeley Heights). Bear right onto Diamond Hill Rd. Follow the instructions above for Summit Medical Group, Lawrence Pavilion.

