

ANA/NJ Newsletter
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**Chapter Meeting, Lawrenceville,
April 7, 2013**

Our Spring chapter meeting was held again this year at the Lawrenceville Branch of the Mercer County Library System, April 7, 2013. There was an excellent attendance of 35 AN patients and caregivers.

Dave Belonger presided. Wilma Ruskin welcomed all and recommended checking out the ANA/NJ discussion group on Facebook.

During the first half of the meeting, discussion generated by the go-round tended to focus on side effects of surgery for AN. Two patients spoke of their different experiences with the combination of microsurgery (partial removal) and Gamma Knife radiation for a large tumor. Also at the meeting were patients engaged in or considering the wait-and-watch option; a CyberKnife treatment patient; several Gamma Knife patients; a neurofibromatosis patient; a surgery patient about to try the SoundBite Hearing System. Two pamphlets circulated during the session: one for the Starkey Company's *Xino Tinnitus*, an in-the-ear sound stimulus device for masking tinnitus; the second to call attention to a new online NF (neurofibromatosis) Registry created by the Children's Tumor Foundation, New York, NY www.nfregistry.org.

The second half of the meeting was a presentation with Q&A for the SoundBite Hearing System by Mike Hendricks, a SoundBite Consultant. Mike introduced SoundBite as a still getting started new hearing system for SSD, but one received very well thus far since bone conduction sound transmission using the teeth means that no surgery is required. There is still no Medicare coverage for the system, and at the list price of \$8000 it is much more expensive than, say, CROS hearing aids. A special introductory price of \$6800 was quoted, hopefully covered mostly by any secondary insurance such as BC/BS. There are physician charges and dental costs to consider. The Sonitus Medical brochure states: "Once prescribed by your treating physician, typically an ENT or Otologist, a simple partial impression of your teeth will be taken. From this impression, a custom-made SoundBite system will be made just for you. You snap it on, it is programmed by your audiologist, and then you are on your way to a new world of sound." The manufactured system package includes two in-the-mouth devices, one behind-the-ear microphone/transmitter, one charger (batteries are rechargeable), and two carrying cases. There's a two-year warranty. Mike noted that New Jersey lags behind in getting ready for the system; Berkeley Heights (Dr. Jed Kwartler) is the only listed participant. Mike distributed copies of the documents needed to initiate manufacture of the SoundBite: (1) the Insurance Benefit Investigation Form (2) Physician Prescription Form & Letter of Medical Necessity (3) Copy of Insurance Cards (4) Current audiogram. There were many questions about the device, mainly concerning the durability of the in-the-mouth piece. Quality of sound compared to the Baha was also a question. Mike invited everybody to try the demo and look over the sample BTE and ITM devices he had brought to the meeting.

Notices

- The CyberKnife radiosurgery system is manufactured by Accuray Inc., a radiation oncology company headquartered in Sunnyvale, CA (www accuray.com). Dr. John Lipani, who reports on CyberKnife hypo-



fractionated stereotactic radiosurgery for acoustic neuroma in this issue of the newsletter, trained extensively at Stanford University under Dr. John Adler, the inventor of CyberKnife. Dr. Lipani recently joined ANA/NJ's Medical Advisory Board.

- Rosemary Gibson, former senior program advisor at the Robert Wood Johnson Foundation and former associate at the American Enterprise Institute, is the author of *The Treatment Trap: How the Overuse of Medical Care is Wrecking Your Health & What You Can Do About It* (2011). She is a very informed and effective speaker. For a video of her talk about the book presented at RWJ University Hospital in July 2010, go to www.BookTV.org and search the Video Library.

Acoustic Neuroma Today

Hypofractionated Stereotactic Radiosurgery for Acoustic Neuroma: The CyberKnife

by

Dr. John D. Lipani

Traditional radiation therapy (RT) typically delivers radiation to a wide target field within the body resulting in the treatment of both the tumor and a significant volume of surrounding healthy tissue. This technology is ideal for tumors that invade the surrounding tissue and when tumor margins are not well defined. In an effort to protect the healthy tissue, traditional RT is delivered in small daily doses or fractions divided into 30-40 sessions. This dosing strategy is commonly referred to as *hyperfractionation*. The sub-lethal daily doses allow healthy tissue to repair itself; a capability not present in tumor cells. However, the total dosage delivered to the patient is limited by the tolerance of healthy tissue in close proximity to the target. In some cases, this limitation may result in the inability to adequately control tumor growth. Regardless, once a patient has received his or her limit, radiation treatment must stop in an effort to prevent healthy tissue damage.



Stereotactic radiosurgery (SRS) devices such as Gamma Knife and CyberKnife are designed to deliver high dose radiation with extreme accuracy, targeting the tumor with minimal damage to the surrounding healthy tissue. Using extreme precision in targeting rather than *hyperfractionation* for protecting healthy tissue enables higher more effective dosing to stubborn tumor cells. Traditionally, radiosurgery was delivered in a single session or fraction. The ablation of the target tissue within a single fraction was compared to the definitive cut using a surgeon's scalpel, hence the term *radiosurgery*. However, even with the extreme precision, in some cases such as with tumors located within the brain or spinal cord, *hypofractionation* (i.e., dose delivery in 2-5 fractions) becomes necessary when protection of even a very small amount of healthy tissue is critical.

The CyberKnife system was one of the first radiosurgery devices to use hypofractionation as an added measure of safety. It allows for less damage to surrounding healthy tissue and for clinicians to complete treatment in 1 to 5 days compared to several weeks required for traditional RT. Hypofractionated SRS using CyberKnife has been performed successfully in cases when single-session SRS treatments are considered too risky, such as with tumors within the brainstem, spinal cord, or optic nerves. The combination of high dose precision and hypofractionation has enabled successful treatment of lesions previously considered untreatable with surgery, radiation therapy, or single-session radiosurgery.

Excellent tumor control rates of 95% or more have been reported with single-session SRS (e.g., Gamma Knife), conventionally fractionated stereotactic radiotherapy and proton beam irradiation. Given the impressive rates of tumor control with these modalities, more attention is being paid to functional outcome such as hearing preservation, as well as trigeminal nerve and facial nerve function. The radiobiological rationale behind fractionation is to minimize radiation-induced normal tissue complications. However, conventionally fractionated treatment schedules typically require multiple sessions over 5 to 6 weeks, which may be inconvenient for those living distant from the radiation facility. Furthermore, when the target tissue's radiation sensitivity approaches that of the surrounding critical tissues, as it does with benign (e.g., acoustic neuroma) compared to most metastatic tumors, stricter treatment limitations using conventional fractionation do not provide much room for improvement.

The treatment strategy for acoustic neuromas at Stanford University has focused on using CyberKnife for hypofractionated SRS in 3 fractions in an effort to maintain high tumor control rates while reducing treatment toxicity. Initial data from Stanford (1999) for 33 patients using 21 Gy in 3 fractions was encouraging. The tumor control rate was 97%. Preservation of useful hearing was 77%,¹ compared to 51% overall hearing preservation in compiled single-session SRS data.² However, dosages used for single-session SRS have been reduced to 12-13 Gy over the past decade, and this has maintained tumor control rates of 95% or more while improving hearing preservation in single-session SRS to 60.5%, according to

¹ J.C.Poen et al, "Fractionated Stereotactic Radiosurgery and Preservation of Hearing in Patients with Vestibular Schwannoma: A Preliminary Report," *Neurosurgery*, 1999;45(6), 1299-1305.

² I.Yang et al, "A Comprehensive Analysis of Hearing Preservation after Radiosurgery for Vestibular Schwannoma," *Jour of Neurosurgery*, 2010;112(4), 851-859.

the analysis by Yang et al, and up to 68-77% in some single-institution reports.³ The reduction of dose also resulted in a decreased risk of trigeminal (0.7-5%) and facial nerve injury (0-4.5%) in single session SRS.⁴

How do more recent CyberKnife hypofractionated SRS results compare to the single-session SRS data? A 2011 Stanford report has looked at 383 cases, 90% of which were treated with 18 Gy in 3 fractions (about equivalent to 12 Gy for single-session SRS). The 3 and 5 year tumor control rates were shown to be 99% and 96%, respectively.⁵ The serviceable hearing preservation rate was 76%. There was no case of facial weakness; eight patients (2%) developed trigeminal nerve dysfunction, half of which was transient.

Although these results are promising, the retrospective nature of this study, along with variables such as tumor size, degree of hearing loss, presence of neurofibromatosis-type 2 and the range of complication rates, make direct comparisons with single-session SRS difficult. However, an interesting observation of the Stanford report is that low risk of complications was seen with larger-volume tumors, perhaps indicating a benefit of hypofractionated SRS compared to single-session SRS in this subset of cases.

The current Stanford protocol for treatment of acoustic neuroma using CyberKnife is 18Gy in 3 daily sessions. Each session lasts approximately 50 minutes. CyberKnife patients do not require the application of a rigid stereotactic head frame. Instead, the patient's face and head are held steady using a soft customized see-through and breathable aquaplast mask. CyberKnife treatment for acoustic neuroma results in excellent tumor control with promising hearing preservation and non-auditory complication rates. Despite these successes, more research is needed to continue optimizing the functional outcomes in these patients and to better distinguish between the various treatment options. Until then, with comparable results across all non-invasive modalities, certain considerations such as number of sessions and frame-based vs. frameless technology may be reasonable when choosing a particular treatment option.



“Critical Decisions” (A Look at Shared Decision Making)

Dr. Peter Ubel's book, *Critical Decisions: How You and Your Doctor Can Make the Right Medical Choices Together* (2012), is an excellent read for patients confronted by medical conditions having several treatment options with different possible, but not always totally predictable, outcomes – like, for example, acoustic neuroma. Dr. Ubel, who is a physician and behavioral scientist at Duke University, doesn't specifically address the acoustic neuroma experience in his book, but his thoughtful analysis of decision making in the 'medical encounter' will enlighten anyone coping with a serious illness. His main goal is to help patients and doctors communicate better with each other to make the best medical choices.

We learned of Dr. Ubel's book while looking into the work of the Informed Medical Decisions Foundation (IMDF), a non-profit organization established by Dr. John Wennberg and other physicians in 1989 to advocate for increased patient involvement in medical decision making. For IMDF, then as now, the goal

³ For example: R.Chopra et al, “Long-term Follow-up of Acoustic Schwannoma Radiosurgery with Marginal Doses of 12 to 13 Gy,” *Int J Radiat Oncol Biol Phys*, 2004;68(3),845-851; T.Hasegawa et al, “Stereotactic Radiosurgery for Vestibular Schwannomas: Analysis of 317 Patients Followed More than 5 Years,” *Neurosurgery*, 2005;57(2),257-65.

⁴ For example: L.D.Lunsford et al, “Radiosurgery of Vestibular Schwannomas: Summary of Experience in 829 Cases,” *Jour Neurosurgery*, 2005;102 (Suppl), 195-99; J.M.Hempel et al, “Functional Outcome after Gamma Knife Treatment in Vestibular Schwannomas,” *Eur Arch Otorhinolaryngol*, 2006;263(8), 714-18.

⁵ A.Hansasuta et al, “Multisession Stereotactic Radiosurgery for Vestibular Schwannomas: Single-institution Experience with 383 Cases,” *Neurosurgery*, 2011;69(6),1200-1209.

has been to move healthcare away from a *paternalistic* model of decision making (‘the doctor knows best’) and build a new model of *shared decision making* – defined on the website as “a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient’s values and preferences.”⁶ Dr. Michael Barry, the president of IMDF since 2009, has described shared decision making as “The Pinnacle of Patient-Centered Care.”⁷ He writes: “Experience has shown that when patients know they have options for the best treatment, screening test, or diagnostic procedure, most of them will want to participate with their clinicians in making the choice. . . Patients should be educated about the essential role they play in decision making and be given effective tools to help them understand their options and the consequences of their decisions. They should also receive the emotional support they need to express their values and preferences and be able to ask questions without censure from their clinicians. Clinicians, in turn, need to relinquish their role as the single, paternalistic authority and train to become more effective coaches or partners – learning, in other words, how to ask, ‘What matters to you?’ as well as ‘What is the matter?’”

IMDF has focused its attention on the development of patient decision aids – i.e., information booklets, DVDs, videos and interactive online tools – with the aim of helping patients prepare to have an informed dialogue with their physicians during the medical encounter. Decision aids examining the benefits and risks of medical screenings, procedures and treatments are designed to help patients arrive at the best decisions in line with their own values and preferences. IMDF now produces decision aids in collaboration with HealthDialog, a private healthcare company headquartered in London.⁸ The current list of IMDF decision aids topics numbers 47, ranging from back pain and breast and prostate cancer to cataract surgery and colon screening. (We can’t help thinking of the famous slogan Sy Syms put on radio and TV: “An educated consumer is our best customer.” Deciding on healthcare is not quite the same as buying clothing, but it can’t hurt to know something about what you’re getting into.)

“Empowering Patients with Information” is the title of Chapter 9 in Dr. Ubel’s book. This is the important chapter where Dr. Ubel reflects on the early years of IMDF and its introduction of the idea of decision aids, and where he makes clear that Dr. Wennberg and the other founders had no intention of empowering patients to become autonomous decision makers. There was no intent to replace ‘The Doctor Knows Best’ with ‘The Patient Knows Best,’ to move from one extreme to another. Instead, they chose the intermediate alternative of shared decision making. Dr. Ubel writes: “These doctors believed in empowering patients through information, but not in order to relegate physicians to the role of information clarifier. They recognized that physicians would almost always play a central role in medical decision making. They just wanted to make sure patients had enough in-formation at their disposal to partner with their physicians, so that . . . patients’ preferences would become part of the conversation.”

Dr. Ubel is a “huge fan” of decision aids and believes they have had a major impact on decision-making. Numerous trials have shown, for example, that patients who use decision aids will more often opt for less aggressive medical treatment than other patients and arrive at decisions that are more consistent with their values.⁹ And yet, says Dr. Ubel, decision aids have still to achieve their full potential. “The vast majority of patients who could benefit from decision aids don’t even know they exist.” Furthermore, providing patients with information is not enough by itself; patients must also want and learn to engage actively with

⁶ The website is www.informedmedicaldecisions.org.

⁷ “Shared Decision Making – The Pinnacle of Patient-Centered Care,” *New England Journal of Medicine*, 366 (March 1, 2012), 780-81.

⁸ The website is www.healthdialog.com. Health-Dialog’s chief science officer, Dr David Wennberg, and Elise Burns describe shared decision making on *YouTube* (April 27, 2011). The Ottawa Hospital Research Institute maintains an A-Z inventory of decision aids at <http://decisionaid.ohri.ca>.

⁹ D.Stacey, M.Barry et al, “Decision Aids for People Facing Health Treatment or Screening Decisions,” *Cochrane Database Syst Rev*, 10 (2011).

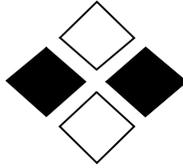
their doctors. As one excellent study by Canadian researchers has observed: “Many patients have been socialized to think that the physician knows best, that they lack the expertise to make the treatment decision that a trusting relationship with the physician means trusting his judgment about the appropriate treatment, or that agreeing with the physician will result in better or more personal care.”¹⁰

In the same vein, Dr. Ubel remarks: “To this day, many patients, especially those with symptomatic acute illnesses, don’t want to be activated; they want to be cured.”

Notice that the title of the Canadian study advises that “It Takes Two to Tango.” Dr. Ubel would agree wholeheartedly. He writes: “We also need to re-educate doctors. The biggest challenge to shared decision making today is not a lack of patient empowerment. As much as we need to increase our efforts to inform patients about their treatment alternatives and to teach them how to be active partners in their decisions, these efforts won’t lead to good decision-making unless patients are paired off with enlightened physicians.” After all, even the most informed patient is no match for the rapid-fire medical verbiage of a too-busy-to-listen or insensitive physician. “Empowered patients,” writes Dr. Ubel, “can’t play an active role in important decisions if they are met on the other end of the stethoscope by poor communicators.” Dr. Ubel’s Chapter 13 therefore deals with “Preparing Physicians for Prepared Patients.” He advocates changes in the way medical students and residents are trained, putting more emphasis in the curriculum on teaching ‘people skills,’ with attention to decision psychology and instruction in body-language recognition.

We’ve thought the best way to end is to recommend Dr. Myles Pensak’s recent article in ANA’s *Notes* (June 2012), entitled “Physician Thinking: Considerations When Helping Patients Make Decisions.” Take a look, or a second look. We think Dr. Pensak practices shared decision making? Do you agree? Note that Dr. Pensak works at the University of Cincinnati Academic Health Center and has the opportunity there to consult with a number of colleagues. How does this affect the decision making process?

¹⁰ C. Charles et al, “Shared Decision-Making in the Medical Encounter: What Does It Mean? (or It Takes at Least Two to Tango),” *Social Science and Medicine*, 44 (1997).



Fall 2013 Chapter Meeting

“What’s New for Acoustic Neuroma?”
(A Look at Two Decades of Change, 1993-2013)

Jed A. Kwartler, MD

Otologist/Neurotologist, Summit Medical Group

Sunday, October 20, 2013

1-3:30 pm

Summit Medical Group

Lawrence Pavilion, One Diamond Hill Road

Berkeley Heights, NJ 07922

A wide-ranging presentation/discussion of changes in the acoustic neuroma experience for both doctors and patients over the past twenty years.

Refreshments Social Time

Directions to Summit Medical Group

The most direct way to the Summit Medical Group facility in Berkeley Heights is via Route 78.

From Route 78 East, take Exit 43, Berkeley Hts/Watchung. Follow the exit road to the light at Valley Rd and turn left onto Valley Rd. Go on Valley Rd to the first light and turn left onto Diamond Hill Rd. Follow Diamond Hill Rd to the light at Mountain Ave. 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 Café/Conference

area. (Note: there is another entrance to Summit Medical Group on the left just before the Mountain Ave light. If you pull in there, just follow the signs for Lawrence Pavilion/Parking Lots 1&2.

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

