



ANA/NJ Newsletter
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ANA/NJ Mini-Conference

April 24, 2016

Sixty acoustic neuroma patients and caregivers attended the April 2016 Mini-Conference held at the JFK Conference Center in Edison, NJ. Special thanks go to Dr. Joseph Landolfi and the NeuroScience Institute at JFK for hosting this very successful event. ANers will recall with appreciation that ANA/NJ's third biennial mini-conference in October 2012 was also held at the JFK Conference Center.



Wilma Ruskin welcomed everyone to the conference and was pleased to recognize some special guests: Lauren Goldberg and Miranda Sacharin, who are co-leaders of the NYC acoustic neuroma support group, and Alan Goldberg, who is the current president of ANAUSA's Executive Board. Wilma introduced Allison Feldman, the new CEO of ANAUSA, who came from Georgia to be with us. It was gratifying to have these special people in attendance at the conference.

Dr. Landolfi added his welcome to all on behalf of the JFK Medical Center and NeuroScience Institute. He then introduced the members of the morning session's Doctors' Panel which dealt with the broad topic "Diagnosis Acoustic Neuroma: What Next?" The panel members were Drs. James K. Liu (Rutgers/Newark), Christopher J. Farrell (Thomas Jefferson University) and John G. Golfinos (NYU Langone Medical Center), as well as Dr. Landolfi.



Dr. Liu was the panel's moderator. He began the session by emphasizing that many different factors are involved when deciding on any treatment for an acoustic neuroma. He listed at least twenty, including patient age and physical condition; the size, nature and location of the tumor; the patient's hearing level at the time of diagnosis; possible surgical approaches; the types of radiation techniques that are available; and willingness on the part of the patient to delay treatment to 'wait-and-watch' the tumor with periodic MRIs.

The panel then began to look at a series of patient profiles and associated MRIs (on screen) for discussion of possible treatment options in each case. For example, Case No.1 was that of a young woman, 38 years old, small tumor, some hearing loss, some tinnitus, experiencing vertigo. The panel agreed this was a complex case with more than one way to go for treatment. Interestingly, Dr. Golfinos observed that there is not a lot of data on treatment outcomes for 38-year-old women. He recommended surgery. The patient, he emphasized, is young, so remove her tumor while it's still small and let her get on with her life. Dr. Landolfi agreed that surgery was a reasonable treatment in this case, although Gamma Knife radiosurgery might also be considered. A recent report from Japan has confirmed the long-term (more than 10 years) safety and effectiveness of stereotactic radiosurgery for small and medium-sized acoustic neuromas

treated with a median marginal dose of 12.8 Gy.¹ There was one main caution: “To retain serviceable hearing, it is important to apply GKS treatment while patients retain Gardner-Robertson Class 1 hearing.”² In other words, those patients who begin with good hearing are most likely to retain good hearing after treatment. Dr. Farrell commented that low-dose fractionated radiation (Linac) is designed to improve hearing preservation. It’s essential to protect the cochlea, which can withstand a radiation dose of only about 4Gy.³ Dr. Farrell speculated during the Q&A that the primary determinant for type of treatment in Case No.1 might not be age or hearing preservation, but rather the patient’s vertigo. That is, in view of the patient’s vertigo, surgery might be most appropriate: “In patients with true vertigo, surgically cutting the vestibular nerve at the time of tumor removal is often the fastest and best way to help with this debilitating symptom.”

During the discussion for Case No. 1, no mention was made of ‘wait-and-watch’ as an option. Dr. Liu finally disclosed that the patient was actually treated by retrosigmoid surgery.

The panel moved on to cases involving large tumors. A critical discussion took place on the current practice of sub-total removals of large tumors followed by radiation treatment of ‘residuals’.⁴ For the large tumor being viewed on screen at the time, a two-stage procedure did not appear to be warranted.

The final MRI viewed by the panel was a case of neurofibromatosis type 2 (NF2) showing an example of very large bilateral acoustic neuromas. Treating this rare inherited condition (only about 5% of AN patients) is very difficult. The panelists noted limited success with the very expensive drug *avastin* (costing about \$13,000 per month). Clinical trials for other, possibly less expensive drug therapies are underway.⁵

The afternoon session of the conference began with a presentation on “Balance and Cognitive Issues” by Dr. M. Lucia Jimenez, who is Director of the Elmhurst Physical Therapy & Balance Center in Queens, NY. Dr. Jimenez earned her MA at NYU and holds a degree as Doctor of Physical Therapy (DPT) from the University of Montana. Her presentation, which made use of slides prepared by VEDA, the Vestibular Disorders Association, was excellent for showing how AN-related vestibular disorders can affect us in many different and often unsuspected ways. In addition to dizziness, vertigo or imbalance, vestibular disorders can lead to feelings of anxiety or panic, loss of confidence, depression and general ‘brain fog’ malaise that may require special types of vestibular rehab therapy. To help, there are different types of vestibular specialists available, as Dr. Jimenez’s presentation made clear. She recommended checking out the valuable VEDA website (www.vestibular.org), which provides a directory of vestibular specialists, a resource library of downloadable booklets, support group information and a ‘Forum’ for VEDA members. The association also maintains a page on Facebook.

¹ T.Hasegawa et al, “Long-term Safety and Efficacy of Stereotactic Radiosurgery for Vestibular Schwannomas: Evaluation of 440 Patients More than 10 Years after Treatment with Gamma Knife Surgery,” *Jour Neurosurgery*, 118 (March 2013).

² T.Hasegawa et al, “Factors Associated with Hearing Preservation after Gamma Knife Surgery for Vestibular Schwannomas in Patients Who Retain Serviceable Hearing,” *Jour Neurosurgery*, 115 (December 2011).

³ See Dr. John Lipani’s discussion of types of fractionated radiosurgery in the *ANA/NJ Newsletter* (June 2013). Newsletter online at www.ananj.org.

⁴ For partial removals and ‘residuals,’ see the *ANA/NJ Newsletter* (Sept 2015 & April 2016).

⁵ As for example at NYU Langone Medical Center. See *ANA/NJ Newsletter* (April 2015), the report on clinical trials by researcher Dr. Matthias Karajannis.



Following Dr. Jimenez’s presentation, the lights in the auditorium were dimmed and the “Meditation Workshop” conducted by Nancy Rothman brought the conference attendees to a quiet and restful end of the day. Dr. Rothman, who has her PhD degree in chemistry, has been practicing many forms of yoga and meditation for over 20 years and finds that successful meditation allows one to breathe deeply and let go of outside concerns and worries. She led the group in sample meditation exercises and discussed the basic principles and techniques involved. We thank her for demonstrating the benefits of meditation.



From Where I Sit: Some Observations

by
Dick Barker

Hi, this is your editor writing. I've been doing the ANA/NJ newsletter for many years now. What have I observed over the years about acoustic neuroma (AN)? Here are some thoughts ~

First of all, I've been impressed that AN has been able to bring patients and doctors together year after year for serious discussion at local support group meetings or regional and national conferences. There's a very impressive support network for AN. Why is this? After all, AN isn't what you'd call an everywhere, TV-known deadly brain tumor; it's quite rare, benign, and treatable, successfully, in a variety of ways. Some of the small ones don't even need to be treated, just watched to see if they're going to become troublemakers down the line.

I don't want to make light of the matter; these ANs can cause a lot of trouble, especially if they're not spotted early on and become overly large. In fact, it was troubling to me to learn that some ANs can be asymptomatic. And the more cases of AN I've read about or have heard described at meetings, the more I've concluded that these things are just downright annoyingly unpredictable. They are a real challenge. Maybe this is why they've consistently generated so much doctor-patient interest and beneficial exchange of ideas in support group settings? What is the best surgical approach to avoid a recurrence of the tumor? Will the tumor respond to radiation treatment? Why do some ANs grow slowly, while others grow rapidly, or stop growing altogether? What about tinnitus? Why is this happening or continuing to happen after treatment? And what about memory loss? headache? balance issues? fatigue? So what is this thing called acoustic neuroma? I gotta talk to someone about this! There's a lot to talk about. Maybe this is why patients and doctors need to get together so often.

I've thought a lot about the history of radiation treatment for AN, which is natural, I suppose, since I had Gamma Knife radiation in 1991 – successfully, I might add. What has interested me is how radiation, in its various forms, has now become an accepted treatment for AN, whereas twenty years or so ago the usual view about radiation among doctors was “the sky is falling!” There were some “You'll fry your brain” warnings. My own ENT was obviously upset when I declined surgery. The Internet had just got going about that time and things could get really nasty on the Web, not just about surgery vs. radiation, but also single-session vs. multiple-session radiation. Patients were taking sides. NIH stepped in to organize a special Consensus Development Conference on Acoustic Neuroma (1991) that proclaimed, cautiously: “Radiation therapy is a treatment option limited in current practice primarily to patients unable or unwilling to undergo otherwise indicated surgery.” This was the controversy Dr. Farrell (Thomas Jefferson University) had in mind at our Mini-Conference in 2014 when he commented about how happy he was that the “Man vs. Machine” years were over. He could now speak freely about fractionated radiotherapy as a treatment option for AN. We've been noting that surgeons are now quite receptive to the idea that partial removals of ANs might be followed by radiation treatment for residuals. I'm not sure that all this was a generational thing; that is, that it takes about 20 years or so for a young group with new ideas to replace an old group with outmoded ideas. My own experience has been that older people (like me) are very receptive to new ideas.

The increase in the number of patients opting for Wait-and-Scan management of their ANs (now about 20%) has been of great interest to me. I think the increase reflects how patients have become more knowledgeable about AN growth behavior. The Internet has been a big factor in this. If I had known more about Wait-and-Scan in 1991, I might have delayed having radiosurgery for my 1.2 cm tumor. A good friend of mine did just that 20 years ago for his 1.7 cm tumor and he has had no regrets. He's still Wait-and-Scan! But I worry now about ANs being so very unpredictable -- what works for one patient may not work for another. Also, there's the recent discouraging news that Wait-and-Scan patients run the risk of progressive hearing degeneration even though periodic MRIs show no tumor growth. To be safe, this

means doing careful monitoring of hearing as well as having the MRIs to check for growth. It's been my observation that doctors are advising early 'hearing preservation' treatment (surgery or radiation) for even very small ANs. For patients, it's a tough call. I still remember that I went for treatment simply because I felt I had to 'do something.' There's a panic factor that kicks in for many of us when a doctor says brain tumor.

I've observed that I'm not very good at advising about patient rehabilitation needs after treatment for AN. I lost hearing in my affected ear, but I've never bothered getting a hearing device, even though they've been getting better and better. For eye and facial nerve problems, headache and balance, ANA has some pretty good booklets, and I've looked at these. But I didn't experience any post-op problems in these areas. With Gamma Knife treatment, it was in and out and back to work. An episode with an abdominal aorta aneurysm in 2006 did wake me up to how traumatic a surgery could be, but even then I was quickly back to normal. Our association members used to talk a lot about rehab problems years ago, but now we mostly discuss treatment options and outcomes. I think it's because MRI is spotting most ANs while they're still small, so that facial nerve damage, for example, is not much of a problem these days. Instead, hearing preservation has become the big issue. And balance (or imbalance) has remained a big concern, although for some of us older folks it's undecided whether AN or AGE is the true culprit. "After it, therefore because of it" may not be the proper logic for explaining every medical problem that comes up in the years following the AN experience.

Treatment for AN has come a long way since the early 1900s when surgeons were reporting anxiously on the number of post-op "survivors." The first complete removal of an AN with facial nerve preservation was in 1931; the first use of the microscope for AN surgery was in 1961; the first brain scan with CT (computer tomography) was in 1971; the first use of the Gamma Knife in the US for radiosurgery was in 1987; and MRI became the preferred modality for imaging at radiation centers in 1991. I was treated with the Model U Gamma Knife in 1991. The radiation dose at the margin was a high 17Gy. Dosages beginning in about 1992 have been lowered to 12-13 Gy and outcomes for patients have definitely improved. Radiation centers are still debating if the best way to deliver radiation for hearing preservation is by single session or by fractionation. There has been rapid improvement in microsurgery since 1961, and in radiosurgery/radiotherapy since 1991. The best neurosurgeons today are really very good at what they do; and the most recent model of the Gamma Knife is actually called "Perfection."

But *Quo Vadis?* (Where are you going? What next?) This was the intriguing question at the end of a report on "Gamma Surgery for Vestibular Schwannoma" prepared in 1999 by the Gamma Knife team at the University of Virginia. The report observed: "The emergence of newer approaches in the management of these and other tumors. . . may someday make surgery with the microscope or the Gamma Knife obsolete. It is humbling to think just how primitive the act of physically cutting out a disease, disentangling it from normal structures, as it were, or for that matter treating it *in situ* with a burst of high energy, would seem in the perspective of time, no matter how refined and glamorous we make it look today." I'm optimistic that we have already moved into an exciting new time of genetic-molecular biology that will see great advancement in the treatment of acoustic neuroma.

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Notices

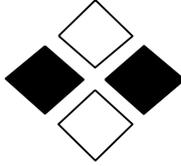
- In N. Boari et al, “Gamma Knife Radiosurgery for Vestibular Schwannoma: Clinical Results at Long-term Follow-up in a Series of 379 Patients,” *Jour Neurosurgery*, 121 (Dec 2014), researchers in Italy reported: “Patients who had vertigo, balance disorders, or facial or trigeminal impairment usually experienced a complete or at least significant symptom relief after treatment. However, no significant improvement was observed in patients previously reporting tinnitus.” See abstract, www.pubmed.gov.
- Weill Cornell in NYC (Dr. Samuel Selesnick) and several other medical centers in the US are seeking to collect data on long-term outcomes in patients having ‘residual’ tumor due to subtotal removal of a large acoustic neuroma 2.5 cm or more in diameter. For information about participating in this study, see “Acoustic Neuroma Subtotal Resection Study (A.N.S.R.S.)” at www.ANAUSA.org.
- Two biologists, Itai Yanai and Martin Lercher, have written an important new book, entitled *The Society of Genes* (Harvard University Press, 2016), that directs attention to how much human genes work together to produce complex biological processes. They illustrate how the easy concept ‘one gene – one function’ must be qualified by the understanding that there are actually networks of cooperation at work among individual genes. Reviewer Joseph Swift (*Science*, 25 March 2016) writes: “Whereas many genes encode for proteins that perform a single monotonous task, such as breaking down a certain type of sugar or producing a skin pigment, there are others that serve such fundamental roles that their removal would lead to the crumbling of the genomic society altogether. Among the latter group are genes that manage the behavior of a host of other genes.” One wonders, how does this relate to studies of the NF2 gene that has been identified as a key player in the genesis of acoustic neuroma?

~In Memory~

Israel Heilweil Doris Pagano Irving Serkin

Long-time members/supporters of ANA/NJ.

We extend sincere condolences to family and friends.



Fall 2016 Chapter Meeting

“Caring and Sharing”

An Open Meeting for Patients, Family & Friends

Sunday, October 23, 2016

1:30 – 4:00 pm

Mercer County Library System

Lawrenceville Branch

2751 Brunswick Pike (Route 1 South)

Lawrenceville, NJ 08648

609-882-9246

Refreshments Social Time

(Send RSVP and /or any questions to Wilma at ananjinc@aol.com, 609-510-9039)

Directions to the Library

From North Jersey: Take Route 1 South. After the I-295 overpass there will be a traffic light at Franklin Corner Rd. Stay to the right onto Business Route 1 and make a quick right at the traffic light onto Darrah Lane. The Library with parking is on the right.

From Trenton: Take Route 1 North to the Whitehead Rd Exit. Make a left onto Whitehead Rd and follow until the traffic light. Make a right onto Business Route 1 and continue North about one mile. Immediately after the third traffic light, move into the jug-handle to cross Route 1 onto Darrah Lane. The Library with parking is on the right.

From Eastern NJ: Take I-195 West to I-295 North. Exit at Route 1 South. Follow the “From North Jersey” directions above.

From South Jersey: Follow I-295 North. Exit at Route 1 South. Follow the “From North Jersey” directions above.