

ANA/NJ Mini-Conference JFK Medical Center, 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 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 NYCity acoustic neuroma support group, and Alan Goldberg, who is the current president of ANAUSA's Executive Board. Wilma also 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

factors, 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



Drs. Golfinos, Farrell, Landolfi

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

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).

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 be not either 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

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* (April 2016).

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

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.



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.



