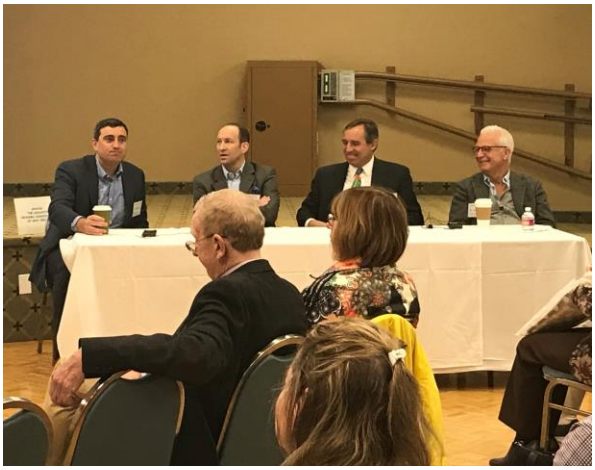
Mini-Conference at JFK, April 22, 2018

Our Mini-Conference held at the JFK Medical Center in Edison, NJ, on April 22, 2018, was well attended and rated as highly successful by those who completed the evaluation form. This was the third mini-conference hosted for us by JFK. It was the first held jointly with the NY City Acoustic Neuroma Support Group. Miranda Sacharin spoke for the NY City group during the 'Welcome' beginning the conference. Unusual greeters this day were two very friendly 'Hearing Dogs,' arranged with our thanks by Melanie Riordan. Present throughout the day was a representative for Oticon Medical, Alison Sabbar, who demonstrated the new Ponto 3 bone-anchored hearing system.

The morning session of the conference featured a distinguished Doctors' Panel for the topic "Wait-and-Scan, Partial Removals, Fractionated Radiation: Exploring the Pros and Cons." Dr. Jed Kwartler (Summit Medical Group) was the moderator. The other members of the panel were: Dr. Christopher Farrell (Thomas Jefferson University Hospital), Dr. Joseph Landolfi (JFK Medical Center), Dr. John Golfinos (NYU Langone Medical Center) and Dr. Philip Stieg (Weill Cornell), as shown from left to right at the speakers' table in the photo.



Dr. Kwartler began with a brief slide-based review of some basic factors influencing treatment decisions for acoustic neuroma: e.g., presenting symptoms such as hearing loss, tinnitus and vertigo; tumor size and location; patient age; concerns about avoiding damage to the 7th cranial facial nerve. The final slide in this review showed a One–Way sign with a large arrow pointing to *Surgery*! But this was only to remind us of what used to be the single, standard treatment for acoustic neuromas. Today's patients and their doctors have a wide range of treatment choices, and increasingly with emphasis on preserving quality of life.

The panelists discussed treatment choices for several 'typical' AN patients. Sample MRIs to initiate discussion were projected on screen for everyone to see. As it proved, surgery was recommended for the first case, a 38 year old man with a very large tumor. Hearing in the affected ear would be lost by the surgery; the main concern was to preserve facial nerve function.

With this concern in mind, should complete resection of the tumor be attempted? Or wouldn't it be safer to do a partial, subtotal removal? But if subtotal, how little 'residual' tumor could be left? Was it even possible to determine this beforehand? There was much to and fro among the panelists about post-surgery outcomes. And then too, since the patient's hearing in the affected ear would be lost, could a Baha hearing device be implanted during the surgery? Perhaps it would be better to wait and do this separately later? To implant later would be a minor outpatient procedure.

A second case was that of a 38 year old woman with a small tumor, mild hearing loss, tinnitus and vertigo. 'Wait-and-Scan' was one recommendation because of the small size of the tumor, and provided the vertigo was tolerable. But there was discussion of the need for more data about long-term outcomes for patients electing this option. Middle Fossa surgery was also recommended: that is, remove the tumor while it was still small, and thereby help remedy the vertigo, and let this young woman get on with her life. Here, for a time, the conversation among the doctors became highly professional and technical. It brought to mind a question of whether or not so-called "shared decision-making" is possible in all cases among patients and their doctors?[1]

Radiation treatment was not discussed as a possibility for this second case. Types of radiation now available would be single session treatment by Gamma Knife or Linac (linear accelerator); 3-5 session hypofractionation by CyberKnife (Linac); or 30 session hyper-fractionation by Linac or even Proton Beam. Just recently (2017), a new "Edge" (Linac) radiation system by Varian (Palo Alto, CA) was announced. The brochure claims: "A growing body of clinical evidence is demonstrating the benefits of delivering high doses in a small number of fractions. . . Stereotactic Radio-surgery (SRS) is progressing to treat targets previously not considered candidates for high-dose, hyprofractionated delivery."[2] But the panelists did not get involved comparing radiation systems or the values of different levels of dose fractionation. They expressed concern mainly about dangers of radiation of large tumors growing near the cochlea or into the brain stem. It was noted that these critical areas cannot sustain high doses of radiation.

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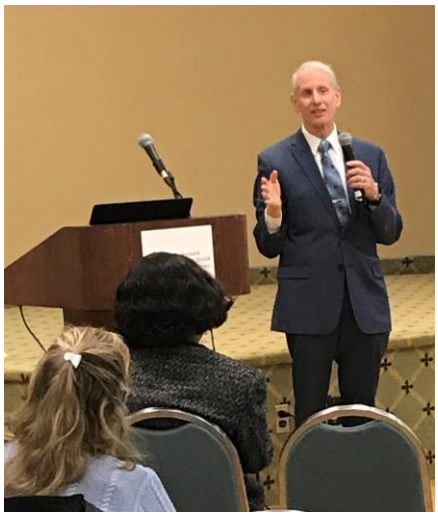
Following a good lunch, the conference continued with the two scheduled afternoon sessions. The first session dealt with "Balance Issues and Vestibular Therapy." The two presenters were Dr. Michael Rosenberg, director of Neuro-Opthalmology at JFK, and Dina Leyden, a specialist in physical therapy at the Summit Medical Group (Berkeley Heights). Dr. Rosenberg's slide presentation helped to explain and distinguish between dizziness problems such

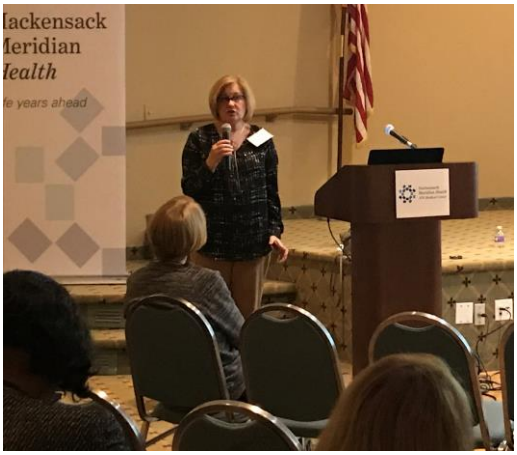


as light-headedness, imbalance and vertigo. He discussed what he likes to call the "Visual Vestibular Mismatch Syndrome" that develops when coordination between vision and vestibular functioning goes awry. For the lively Q&A, Dr. Rosenberg and Dina Leyden team-answered nicely a variety of interesting questions related to individual experiences with balance problems and therapy.

The second afternoon session dealing with "Tinnitus Issues and Hearing Assistive Devices" was presented by Dr. Virginia Toth, who is the

[1] See "Critical Decisions (A Look at Shared Decision-Making)," in the ANA/NJ Newsletter (June 2013).

[2] See Edge Radiosurgery System, www.Varian.com.



manager of audiology programs at JFK. Dr. Toth gave an excellent description of the nature of single-sided deafness (SSD) and its problems. She cautioned that for many people "One ear is really not good enough." She reviewed the variety of assistive hearing devices available for SSD today.

As for tinnitus, no recently discovered 'cure' could be brought to our attention. But for help 'getting used to it', Dr. Toth recommended proven habituation systems such as Tinnitus Retraining Therapy (TRT) or Neuromonics, or perhaps using a hearing aid. Some people have tried acupuncture, hypnosis or B vitamins, but there is little evidence that this work. She warned definitely against using ear muffs or ear plugs. Among the things that can be helpful, Dr. Toth recommended: investigating coping strategies; participating in a tinnitus support group; avoiding irritants and stress; trying soft music to mask the tinnitus; and limiting alcohol consumption.[3]

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[3] For a list of tinnitus support groups and phone 'help network' volunteers in NJ, see the Sept 2014 issue of the Newsletter.