

**ANA/NJ Newsletter**  
**Vol. XII, No. 2, September, 2010**

**Winter Meeting, March 27, 2010**  
**Voorhees, NJ**

The Winter “Share & Care” meeting originally scheduled for February 6, 2010, was held March 27 at the Camden County Library in Voorhees, NJ. Board members Tim and Karen Reid organized the meeting and provided the refreshments. Among the fourteen people attending, two were new to the AN experience, two were due for surgery in about three weeks, three were caregivers, and the others were “AN old-timers.” There was lively discussion. The new ANA/NJ T-shirts and wristbands were introduced at the meeting and proved to be very popular.

**Spring Chapter Meeting, April 18, 2010**  
**Berkeley Heights, NJ**

The Spring meeting presented “Coping with the Aftermath of Acoustic Neuroma: An Informal Patients Panel & Discussion.” About 40 people attended. Dick Barker introduced the patient-panelists: Phil Stern (headaches), Margie Wasserman (balance problems), Alix Garzero (fatigue), Debbi Bifulco (facial/eye issues) and Mike Illuzzi (tinnitus). The panelists each described their personal encounters with acoustic neuroma and how they tried to cope with the experience. Phil Stern recalled his years of severe, debilitating headaches following surgery and his experimentation with a great variety of ways to bring them under control (See Phil Stern at “Stories” at [www.ananj.org](http://www.ananj.org)). Margie Wasserman related how Gamma Knife treatment in 2006 followed by surgery in 2007 caused severe balance issues that only persistent vestibular therapy helped to resolve. Alix Garzero described how the very long surgery in 2000 for her 4.8 cm tumor resulted in extreme fatigue lasting three months, among even more serious problems. Debbi Bifulco reported on coping with post-surgery right-side facial paralysis and demonstrated the “tools of the trade” she has used for a severe dry eye condition. And Mike Illuzzi, a wait-and-watch patient with a 6x12 mm tumor, described his long experience with tinnitus and the benefits of the new Neuromonics treatment he has undergone (See Mike’s “Spotlight” in the Newsletter, April 2009). There was good discussion following the presentations, and, we noted, much useful exchange of information.



**Notices**

- We are happy to announce that Debbie Bifulco (Newton) and Donna Carides (Bedminster) have been elected members of the ANA/NJ Board of Directors. Suzanne Milano (Warren), recently “on leave,” has rejoined the Board. Welcome all!
  
- Summit Medical Group has announced that Dr. Jed A. Kwartler has become the “first and only physician in New Jersey to become board certified in neurotology.” Congratulations to Dr. Kwartler.

- The Steeplechase Cancer Center at Somerset Medical Center, Somerville, NJ, is using the Novalis Tx linear accelerator for stereotactic radiosurgery/radiotherapy treatment of acoustic neuroma. Dr. Joel Braver is medical director of radiation oncology at the Center. For more information about the Center, call 908-927-8777 or go to [www.somersetmedicalcenter.com](http://www.somersetmedicalcenter.com).
- The Brain Tumor Foundation located in New York City has updated its website for brain tumor patients and caregivers. The site provides an online forum, news, information about events for brain tumor patients, and other features. Call 212-265-2401, or go to [www.braintumorfoundation.com](http://www.braintumorfoundation.com).
- A medical journal article reviewing the risk of radiation-induced tumors following radiosurgery or radiotherapy has been published by Drs. Niranjan, Kondziolka and Lunsford of the Center for Image-Guided Neurosurgery of the University of Pittsburgh Medical Center: "Neoplastic Transformation after Radiosurgery or Radiotherapy: Risk and Realities," *Otolaryngol Clin North America*, vol.42, August 2009, pp.717-29. The authors conclude that the risk is very low.
- The national ANA has issued the advisory that the best interpretation of the 25 epidemiologic studies published during 1999-2008 is that the results do not demonstrate an increased risk of developing an acoustic neuroma for frequent cell phone users. In this regard, the results have been inconclusive.

### **Medifocus Guide for Acoustic Neuroma**

Medifocus.com in Silver Spring, MD, which describes itself as a "clearinghouse for medical health information," produces separate guidebooks for over 120 medical conditions, including acoustic neuroma. These are available in both print and electronic formats. We have looked at the print copy of the July 2009 edition of the Guidebook for acoustic neuroma, 133 pages, \$26.95 plus \$6 shipping. Some observations are as follows:

- The 2009 Guide is much expanded and much better than the 2005 edition. There are six sections.
- Section 1, "Background Information," gives useful tips for conducting advanced research on acoustic neuroma.
- Section 2, "The Intelligent Patient Overview," (30 pp) is the core and probably most important part of the Guide. It presents an in-depth discussion of acoustic neuroma: incidence, symptoms, testing, diagnosis, tumor growth rates, treatment options, possible complications, quality of life issues, new developments. References to medical journal reports are provided throughout. One caveat is the section's oddly outdated presentation of radiosurgery/radiotherapy as a risky "second-line treatment modality." The section needs to be brought up-to-date for the advances in radiation treatment outcomes since dose reductions to 12-13Gy, and for the current widespread recognition of radiosurgery/radiotherapy as an appropriate and safe treatment option.
- Section 3, "Guide to the Medical Literature," (37 pp) especially attracted our attention because of its lengthy bibliography of important medical journal articles on acoustic neuroma culled from the National Library of Medicine's PubMed database. The articles were selected to provide advanced information on the treatment and management of acoustic neuroma. The PubMed abstracts of these articles can be accessed using the electronic format of the Guidebook. This is a valuable, time-saving tool for patients

looking for more than basic information about acoustic neuroma. It should be noted, however, that the national Acoustic Neuroma Association now provides a selection of important medical journal articles directly on its website.

- Section 4, “Centers of Research,” lists “leading” doctors and institutions for AN in the USA and other countries. Strangely missing are, for example, Derald Brackmann (CA), Ladislau Steiner (VA), Michael Sisti (NY) and David Andrews (PA).
- Section 5, “Tips on Finding and Choosing a Doctor,” has many helpful suggestions, including the finding that “how long a physician has been in practice does not necessarily correlate with a high level of medical care.”
- Section 6, “Directory of Organizations,” will be useful to patients, although we miss mention of key organizations such as the American Tinnitus Association and American Brain Tumor Association.

### **Causes of Fatigue**

An article on the American Brain Tumor Association’s website ([www.abta.org](http://www.abta.org)), “Help with Side Effects – Fatigue,” offers the following concise statement concerning the causes of the special type of fatigue experienced by patients undergoing treatment for a brain tumor:

*Researchers are still unsure of the exact causes of disease-related fatigue. It is possible that the disease, or the treatments, lower blood counts and those lowered counts cause fatigue. Or, the tumor may release substances that cause a chain-like set of events ending in fatigue. The emotional impact of receiving the diagnosis, the trauma of surgery, the treatments required to kill tumor cells may all add to this extreme tiredness.*

### **Integrative Medicine**

Integrative medicine supplements conventional medicine with complementary and alternative medicine therapies that are not part of standard medical treatment but which have been proven to be both safe and effective. The National Center for Complementary and Alternative Medicine, an agency of the National Institutes of Health, advises health professionals regarding the safety and effectiveness of the therapies. Some of the therapies should be of value to acoustic neuroma patients for help with problems such as headache, imbalance, tinnitus or fatigue.

Dr. Nancy Cotter, Medical Director of Atlantic Integrative Medicine’s Mind Body Center at Morristown Memorial Hospital, introduced us to this rapidly growing field of medicine at our October 2008 mini-conference (Newsletter, April 2009). The Morristown center, established in 1993, offers services in five complementary and alternative medicine categories: (1) *Whole Medical Systems*, such as Tai Chi, Qi Gong, acupressure, acupuncture, Chinese herbology ; (2) *Mind Body*, such as Tai Chi, yoga, zen meditation, hypnotherapy; (3) *Biologically-based Practices*, such as Chinese herbal medicine, diet, nutrition counseling; (4) *Manipulative Practices*, such as physical therapy, massage, acupressure; and

(5) *Energy Medicine* forms of hands-on healing and stress reduction techniques, such as Reiki, Healing Touch, Brennan Healing, polarity therapy.

(See [www.atlantichealth.org/Morristown](http://www.atlantichealth.org/Morristown))

Most large hospitals and medical centers offer integrative medicine services. At Memorial Sloan-Kettering Cancer Center in New York City, for example, the chief of the Integrative Medicine Service is Dr. Barrie R. Cassileth, who currently heads a department there of about 60 people. Before joining MSKCC, Dr. Cassileth was professor of medical sociology at the University of Pennsylvania School of Medicine. We first called attention to the innovative work of Dr. Cassileth in 2003 (Newsletter, June 2003) at the time she was busy creating the internet site named "About Herbs." This important database ([www.mskcc.org/aboutherbs](http://www.mskcc.org/aboutherbs)) has become a top health resource for information regarding herbs, botanicals, vitamins and other over-the-counter agents. As the *MSK Center News* (October 2009) reports: "Managed by pharmacist K. Simon Young, the site is accessible at no cost to visitors. For each herb, vitamin, or botanical, there are two listings -- one for patients and one for oncology professionals -- which include purported uses, possible side effects and interactions, and any clinical trials of the supplement." In 2005, the National Institutes of Health awarded MSKCC \$8 million over five years to serve as one of six botanical research centers. The center works in collaboration with the Institute of Chinese Medicine in Hong Kong.

Dr. Cassileth is the founding President of the International Society for Integrative Oncology. She is dedicated to making the Integrative Medicine Service at MSKCC a prototype program for other institutions. Studies have shown that cancer patients have reported a 50% reduction in pain and stress after one 20-minute massage session, and acupuncture has helped control symptoms related to cancer and its treatments, including pain, anxiety, depression, dry mouth and shortness of breath. The Integrative Medicine Service at MSKCC offers training programs and certification courses for practitioners.

Dr. Cassileth notes: "We've entered a new era of oncology. As survival rates have improved, the control of treatment-related physical and emotional symptoms and patients' quality of life has become a major focus." One cannot help but think of how advances in treatment for acoustic neuroma have given rise to increased concerns for patients' quality of life.

## Reports on Tumor Regrowth

The following reports on regrowth of acoustic neuromas are from PubMed abstracts of medical journal articles ([www.pubmed.org](http://www.pubmed.org)). Full references will be provided on request.

The first 4 reports concern the greater risk of recurrent tumors for patients having incomplete surgical removal of an acoustic neuroma.

- Hospital of Sainte-Margarite, Marseilles, France (2008) reports on its long-term retrospective study indicating a 9.2% regrowth rate for tumors treated by the translabyrinthine approach, “mainly due to regrowth of microfragments that have been left in the operative field along the course of the facial nerve or at the surface of the pons.”
- Dept of Otolaryngology, Univ of Michigan (2000) reports on 39 patients who underwent incomplete removals, 1988-93; 17 (44%) had tumor regrowth. Mean follow-up period of 6.2 years. Ten patients required additional treatment during the follow-up period.
- Dept of Otolaryngology, Univ Hospital of Grenoble, France (2005) reports no tumor regrowths for 91 patients having total tumor removals using the translabyrinthine approach. Mean follow-up period of 11 years.
- Kangwon National Univ, S.Korea (2006) compares outcomes for 116 patients who received either total tumor removal, near total removal or subtotal removal. The regrowth rates were: total, 3.8%; near total, 9.4%; and subtotal, 27.6%. Total removal was found to be the ideal surgical treatment, but near total a good option “with better facial nerve function preservation than [total removal] without significantly increasing the risk of recurrence.”

The following 4 reports concern tumor growth control related to low dose radiation treatments:

- Univ of Heidelberg, Germany (2010) compares 30 patients treated with Linac single-dose radiosurgery (SRS) and 172 patients treated with Linac fractionated radiotherapy (FSR). Median single dose for SRS was 13 Gy; and median total dose for FSR was 57.6. Tumor control rates were found comparable, and SRS a safe alternative to FSR.
- Dept of Neurological Surgery, Mayo Clinic (2009) reports 15 (5%) of 293 patients, 1990-2004, showed continued tumor growth following low-dose (mean 13 Gy) radiosurgery treatment. Distortion of MR imaging and dose reduction “likely caused some [acoustic neuromas] to receive less than the prescribed radiation dose to the entire tumor volume.”

- Thomas Jefferson Univ, Philadelphia (2009) compares 43 fractionated radiotherapy patients treated with 50.4 Gy and 46 fractionated radio-therapy patients treated with 46.8 Gy. The tumor control rate was 100% for both cohorts. The hearing preservation rate was greater for the lower dose cohort. Additional dose reduction is proposed to identify the optimal dose that will yield the greatest hearing preservation rate without compromising tumor control.
- Hospital of Saint-André, Bordeaux, France (2006) reports on 45 cases of fractionated radiotherapy (FSR), 1986-2004. Median total dose of 51 Gy. Median follow-up of 80 months. Following treatment, continued tumor growth occurred for 3 patients (7%) 12 to 15 months after FSR. Two other tumors regrew after initial shrinkage; one of these transformed after 216 months to a low-grade malignant nerve sheath tumor. Caution is advocated when using FSR for young patients.

### **Update on Second Radiosurgeries**

Our article in the September 2008 Newsletter (“Acoustic Neuromas that Enlarge after Gamma Knife Radiosurgery”) noted there is little data regarding the effectiveness of a second Gamma Knife radiosurgery following a failed initial treatment.

Just recently, the New England Gamma Knife Center reported on 11 patients who were retreated in the period 1994-2007. One of the patients had proton-beam radiotherapy as the first treatment, while the 10 others had Gamma Knife initially. The prescription dose for all Gamma Knife treatments was 11-13.2 Gy. “Of the 11 patients, 2 showed increase [in tumor size], 1 had no change, and, in 8, the [tumor] decreased in size after the treatment.” “All patients demonstrated stable facial nerve function.” Regarding facial numbness, 2 patients experienced increases, 8 no change, and one decreased.” Ten patients had no functional hearing before retreatment, and hearing was impaired in one patient. (See S.Dewan & G.Noren, “Retreatment of Vestibular Schwannoma with Gamma Knife Surgery,” *Jour Neurosurgery*, vol 109, Dec 2008).

Also, neurosurgeons in Marseilles, France, have published a study that looks closely at eight cases of repeat Gamma Knife radiosurgery (GKS). For the eight cases, the median prescription dose for both first and second treatments was 12.0 Gy, and the median period of follow-up after the second radiosurgery was 64 months. All eight repeat radiosurgeries were successful, showing either reduction in tumor volume (6) or stabilization of tumor growth (2). Useful hearing ability was preserved in one of the three patients who had serviceable hearing ability at the time of the second GKS. There were no cases of facial nerve dysfunction. The report abstract concluded that “repeat GKS with a low marginal dose seems to be a safe and effective treatment in selected patients harboring regrowth of small vestibular schwannomas that have previously been treated with GKS.” (See S,Yomo, P.H. Roche et al, “Repeat Gamma Knife Surgery for Regrowth of Vestibular Schwannomas,” *Neurosurgery*, vol 64, Jan 2009).

### **Acoustic Neuroma Research Report**

At the 2009 ANA Symposium in Chicago, Dr. Bentley Welling (Ohio State University) reported on "Recent Research in Acoustic Neuromas." He reported that, at present, some sixteen years after the gene "Merlin" for schwannoma cell growth was discovered, research continues actively to find an ideal drug for inhibiting acoustic tumor development. His own research team at Ohio State, aided by a grant from the Institutes of Health, has been busy investigating a wide variety of drugs, including the angiogenesis inhibitor "Avastin." (See ANA/NJ Newsletter, April 2006). AN patients have assisted the research by contributing schwannoma cell samples. The work is steady but slow, and very expensive, in particular for the large number of mouse MRIs required. One possible spin off of the research could be a drug to make tumors more sensitive to radiation treatment. To date, no approved drug treatment for preventing acoustic neuroma has been found.

### **ANA/NJ Mini-Conference**

**October 24, 2010**

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# ANA/NJ Mini-Conference

## “Diagnosis Acoustic Neuroma – What Next?”

Sunday, October 24, 2010 10:00 a.m. – 3:00 p.m.

Summit Medical Group

Lawrence Pavilion, One Diamond Hill Road

Berkeley Heights, NJ

### Program

<b>Registration &amp; Coffee</b>	10:00 – 10:30
<b>Welcome by Wilma Ruskin, President of ANA/NJ</b>	
<b>Doctors’ Panel: “Patient Profiles -- Treatment Options”</b>	10:45 – 12:15
Dr. Jed A. Kwartler (Summit Medical Group), Moderator	
Dr. John G. Golfinos (NYU )	
Dr. James K. Liu (UMDNJ)	
Dr. Michael Schulder (NSU, LIJ)	
Dr. Philip E. Steig (Weill Cornell)	
<b>Lunch</b>	12:30 – 1:15
<b>“Vestibular Rehabilitation”</b>	1:15 – 2:00
Dr. Michael Rosenberg (JFK Medical Center)	
<b>Informal Discussion Session for Patients &amp; Physicians</b>	2:15 – 3:00

(Mail in registration by September 30, 2010. For assistance, call Jane Huck, 908-725-0233)

### **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.