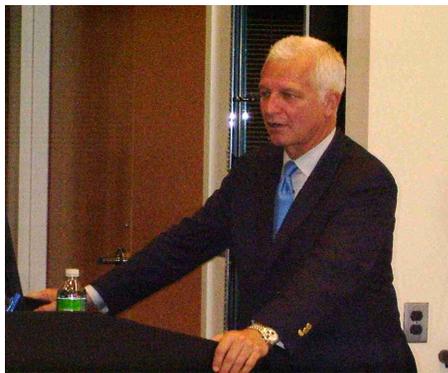


## ANA/NJ Newsletter

Vol. XII, No. 1 (April 2010)

### Chapter Meeting October 11, 2009 Berkeley Heights, NJ

Suzanne Milani introduced our speaker, Dr. Philip E. Stieg, Chairman of the Department of Neurological Surgery, Weill Cornell Medical College at the New York Presbyterian Hospital. ([www.cornellneurosurgery.org](http://www.cornellneurosurgery.org)) Dr. Stieg received his MD degree at the Medical College of Wisconsin in 1983. He was awarded a Fellowship at the Karolinska Institute in Stockholm, Sweden. Dr. Stieg's topic for the meeting was "Acoustic Neuroma: A Time for Surgery." About 25 people attended the meeting.



Following Dr. Stieg's presentation, there was a very lively Q&A period.

Dr. Stieg began his presentation by observing how much things have changed since the time of the first acoustic neuroma surgery in 1894, when doctors talked to patients about the high risk of dying, to our own day, when most doctors stress the importance of maintaining quality of life following a successful surgery or radiation treatment. The very content of Dr. Stieg's talk in fact illustrated throughout that the art of medicine is truly a line, not a point, and along the line how much change there has been in the last twenty years especially. He spoke about how microsurgical techniques now save facial nerve function for most patients; how hearing preservation rates have steadily improved; how older patients with small tumors have learned to watch-and-wait; how early treatment of young patients helps with hearing preservation; the variety of effective radiation treatments now available for most patients; how doctors have learned to combine surgery and radiation; tumor size as a key factor in determining treatment outcomes; how appropriate wound treatment will help to avoid postoperative headache. Along the way, he noted some of his own personal opinions: that cell phone usage is not a problem; that prior radiation makes subsequent surgery more difficult.

Dr. Stieg made clear that he believes informed patients need to be involved in making choices about their treatment. He distinguishes between the "business of medicine" (selling one type of treatment) and the "art of medicine" (informing patients of all treatment choices). His excellent presentation was an example of the art of medicine.

## Notices

● Anyone interested in volunteering to serve on the ANA/NJ Executive Board should please contact Wilma Ruskin at 609-799-4442 or [ananjinc@aol.com](mailto:ananjinc@aol.com). New board members are needed and are always welcome for the different experiences and ideas they bring to meetings. Please talk with Wilma about becoming a member of the board.

●An article in *USNews&WorldReport* entitled “Patients Making Their Voices Heard” (December, 2009) reports that 12 medical centers in the USA are testing a formal process of “shared decision making” for health conditions such as early stage breast and prostate cancer, lower back pain and coronary heart disease. One participating physician has observed: “Patients, when well informed, will make different decisions than doctors – with no adverse outcomes, and maybe better outcomes.” Supporting the work of the centers is the Foundation for Informed Medical Decision Making. The website reports: “A recent survey of patients conducted by the University of Michigan found that fewer than one in five was asked by their health care provider about their preferences for care. Less than 50% were able to answer basic questions about their condition and its treatment. . .The survey also found that providers often neglected to tell patients about the potential disadvantages of treatments or tests that they recommended.” (See [www.informedmedicaldecisions.org](http://www.informedmedicaldecisions.org))

●The FDA has warned that use of the contrast dye gadolinium is contraindicated for patients who suffer from acute or chronic kidney disease. Such patients may run a risk of NSF, nephrogenic systemic fibrosis, a rare skin/joint disorder. MRI patients should inform their doctor and radiologist of any serious renal condition. (See [www.pathmax.com/dermweb](http://www.pathmax.com/dermweb), website of the International Center for NSF Research)

●The Acoustic Neuroma Association provides PubMed abstracts of important medical journal articles about acoustic neuroma directly on its website, [www.anausa.org](http://www.anausa.org). Click on the Members Only button on the homepage, type in username and password, and go to the link for Medical Journal Articles. You will also find the Physician’s Directory and the Medical Centers Directory. (For information about PubMed and the National Library of Medicine, see ANA/NJ Newsletter, Sept 2007)

## **The ANA Patient Survey, 2008: Some Observations**

The results of ANA’s Patient Survey for 2007-2008 are available online and reports on the survey have been published in *ANA Notes*, Issue 108 (Dec 2008) and Issue 110 (June 2009). Some highlights of survey findings are as follows:

- The respondents were 62% female and 38% male.
- Single-sided hearing loss (88%), tinnitus (73%) and vertigo or balance disturbance (59%) were the three most reported symptoms of AN.
- More patients (73%) than in the 1983 (57%) or 1998 (64%) surveys reported tinnitus as a symptom.
- Tumor size at initial diagnosis showed a decrease compared to past surveys.
- Of the 1,967 participants in the survey, 8% did not know the size of their tumor at diagnosis.
- The percentage of patients treated by microsurgery (60%) has decreased while those opting for radiation treatment (20%) or watch-and-wait (20%) has increased.
- 49% of patients who had surgery reported no complications following their surgery.
- The largest number of rehabilitation therapies after treatment was reported by microsurgery patients.
- Tumor regrowth following initial micro-surgery was reported at 7%.
- The majority (77%) of watch-and-wait patients reported no change in size of tumor from initial diagnosis to time of survey (average 4.2 years).
- Of the 271 patients who had single-dose radiosurgery, 194 (72%) did not know the marginal radiation dose that they received.

Acoustic neuroma patients have become increasingly concerned about quality of life issues. Appropriately, the survey reports extensively on pre-and post-treatment experiences for 15 AN symptoms: hearing loss, tinnitus, balance problems, facial weakness, headaches, eye problems, change in smell or taste, facial twitching, facial numbness, ear fullness, difficulty swallowing, difficulty concentrating, fatigue, depression, memory difficulties. The data is presented according to treatment type in tables that show the incidence of the symptoms “At Initial Diagnosis” and “At Present” (i.e., at the time the survey was completed). There is a helpful Chart No.1 bar graph for comparing percentages of “Respondents Reporting Symptoms by Treatment Type.” It should be noted that tumor size has not been factored in for any of these comparisons. In other words, for example, differences in post-treatment hearing loss or severity of headaches are not related to initial tumor size. Our understanding is that ANA is working to use the data generated by the survey to create a searchable online database that will incorporate key factors such as tumor size. Patients will be able to use the database to make all the special comparisons they would like to see.

Users of the survey are advised that “The information from all ANA surveys was self-reported. No attempt was made to confirm or verify the accuracy of reported data. The results are a compilation of this self-reported data only. They are not intended to provide conclusive information regarding causality.”

The 2008 data for “Memory Difficulties” was interesting to consider. For one thing, since the ANA survey in 1998 did not cite memory problems as a patient symptom at initial diagnosis, ANA/NJ reported in its April 2008 newsletter that memory problems for AN patients were post-treatment. This was an error. Actually, as the 2008 survey reports, most AN patients who experienced memory problems did so before treatment, and these problems continued or even increased in frequency after treatment. That this was the case for Watch & Wait patients is particularly significant. Among this group of 380 respondents, 54 (14%) reported experiencing memory difficulties at initial diagnosis of their AN, and about one-third of these said that their difficulties increased in frequency during an average time of 4.2 years from diagnosis to the time of the survey. The big question is: why did memory difficulties worsen during this time for these untreated Watch & Wait patients? In response, we can cite the following reported data for consideration:

- From “At Initial Diagnosis” to “At Present,” there was the average time lapse of 4.2 years.
- During this time, tumor size changed (increased in size?) for 23% of the 380 patients in the Watch & Wait group.
- The “At Present” data for the respondents with memory difficulties shows increasing problems with hearing, concentration, tinnitus and fatigue.
- The “At Present” data shows some but fewer problems with depression, balance and headaches.

Perhaps, as in the article in this newsletter on “Acoustic Neuroma & Memory Problems” (April 2007), we should simply once again underscore the importance of “attention-busters” such as hearing loss, tinnitus, fatigue and difficulties with concentration. As we quoted: “The true art of memory is the art of attention.”

We had some difficulties with terminology used for this report. Most confusing, the term “Symptoms” is used both for evidence of a tumor and for problems or complications resulting from the treatment of the tumor. The report states: “All symptoms reported are those experienced by respondents regardless of their treatment status. The reader can delve into each symptom reported on a pre- and post treatment basis to determine if the symptom appears to be associated with the existence of the tumor

or if it appears to be the result of treatment.” But when using the “At Initial Onset” & “At Present” tables for symptoms, this distinction will not be easy to make. It will be difficult, too, for many AN patients to accept that various post-treatment complications such as facial/eye weaknesses should be called “Symptoms.” Curiously, the term “Complications” is reserved in the report for relatively rare occurrences such as CSF leak and hydrocephalus. The more common and distressful facial/eye complications are found identified and subsumed under the rather neutral heading of “Post-Treatment Rehabilitation Therapies.”

Tumor regrowth following microsurgery was reported at 7%. This rate of regrowth appears a bit high; possible errors in patient self-reporting are examined. Recently, at the 2007 International Conference on Vestibular Schwannoma in Barcelona, Spain, the incidence of tumor regrowth, with variation depending on level of experience, was quoted as 0.3-3% for microsurgery and 2-6% for radiosurgery (See ANA Notes, Sept 2007). The 2008 survey gives no figures for radiosurgery or radiotherapy.

Preservation of useful hearing has been a main area of concern for AN patients. Readers of the 2008 survey will want to review the data it provides for post-treatment hearing outcomes for single-dose radiosurgery (SSR) and fractionated radiotherapy (FSR). The report shows that these types of radiation treatment were administered mainly (91%) during the period 2000 to 2008. Tumor size is not recorded for specific outcomes, but the report shows that most tumors treated were 2.5 cm or below. The “Hearing Statistics” tables in the report show: for 239 SSR patients, 45% had Class 1-2 hearing ability 1-2 hearing ability before treatment and 26% following treatment. About 32% of survey respondents for both SSR and FSR were unable to provide data on their hearing ability before or after treatment.

### **Victor Mankoski in the Spotlight**



Loyalty to family, friends and place are strong threads woven through Victor Mankoski’s life. He lives close to where he grew up, has been married for 34 years to a woman he has known since kindergarten and maintains friendships that go back even further. Victor and his wife Linda were in the same high school class, had many of the same friends and will soon attend their 45<sup>th</sup> year HS reunion together. He did attend college in Missouri and Connecticut but then returned to NJ and got his graduate degree at Jersey City State College and his certification as a school administrator at Seton Hall University.

Victor took a life transforming job in 1966, after his freshman year in college, as a lifeguard at Woodbridge State School. There he discovered his love of working with special needs kids. “They made me feel so special.” Those pivotal relationships with the kids and their families, like so many of the relationships in his life, have been maintained over the years. As a result of this experience, Victor commenced a career working with the disabled, first as a special education teacher and later as a supervisor, a Vice Principal and then Administrator.

Victor and Linda raised their two children, Sara and Seth, around the corner from where they have now lived for the past 16 years. Their lovely home is warm and welcoming and Victor is rightfully proud of the great room which he designed himself. Victor is now retired and is enjoying pursuing his lifelong interest in art by taking water color painting classes two or three times a week. He also takes disabled adults bowling one day a week for the Arc of Union County.

In 1999, Victor was out walking one day in his quiet residential neighborhood when he heard what sounded like two gunshots followed by muffled hearing. A few days later his hearing returned, but a month later the same thing happened. A nurse practitioner advised him to go see an ENT who then sent him for an MRI. The ENT said it was a million to one that it would result in anything, but when he saw the negative results along with the actual MRI, he did not feel what he was seeing matched the written report. He sent Victor for a closed MRI which showed that he had an 8.5 mm tumor on his vestibular nerve.

Victor explored his options visiting several doctors before making his decision for surgery. He visited Drs Kwartler and Hodosh in Summit, and then went to Thomas Jefferson Hospital in Philadelphia where he met and really liked Dr. Sataloff. However, after surgery was scheduled for the summer of 2000, Dr Sataloff informed him that the procedure he would use would be the translabyrinthine approach which would render Victor deaf in the affected ear. Having done his homework and read about the three surgical options, Victor questioned why he wouldn't do a middle fossa procedure for such a small tumor. He asked where the best place to go for a middle fossa procedure would be and was given the name of House Ear Clinic in California. He located them on the internet and called them. Within a half hour Victor received a call back by one of their interns, a Dr Chen from Australia. Dr Chen confirmed that with such a small tumor a middle fossa approach would be best and asked that the tests be mailed to House Ear for review. Victor overnight mailed the tests to House Ear and had a return call from Dr Slattery who advised that he would be a good candidate for the middle fossa approach and gave Victor references to call. Victor called those references and all of them said good things about House Ear. When he advised the doctor from Philadelphia of his decision, Dr Sataloff advised that he could also do a middle fossa procedure but conceded that this procedure would involve more risk since he did not do it regularly.

Victor cannot say enough good things about the treatment he received from House Ear in the summer of 2000. He and his wife spent about three weeks in California and made good friends with three other patients and their spouses who were staying in the same place and going through the same procedure. He spent three days in ICU then another four days in the hospital. They then stayed in the area for two weeks after the procedure as advised for follow up. Victor was able to do a lot but did fatigue easily. He returned to work after Thanksgiving and even went snow skiing that winter having resumed a normal schedule. His fatigue and balance issues were pretty much resolved by May or June of 2001.

For the first five years, MRI's were negative and all was well. When Victor had his seven-year follow up MRI he was shocked to be told that not only did he have another tumor but it was already 2.5 by 3 cm and was on his facial nerve. This was devastating. Not only did House Ear tell him that they couldn't do a middle fossa procedure, they were even hesitant to do the translabyrinthine procedure because of the risk to his facial nerve. They asked him to consider radiosurgery, but he was concerned about possible complications which might result if he was to have a 3<sup>rd</sup> tumor. As a result Victor made the decision to return to House Ear for microsurgery. Again it was an amazing experience. When Victor and Linda returned to California, now in 2007, they were met by some of the same staff as they had dealt with before. He was greeted as an old friend at the hospital residence where Linda stayed while Victor was hospitalized. He was similarly greeted in admissions, and by the recovery nurse and anesthesiologist.

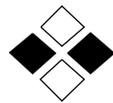
Drs Hitselberger, Neurosurgeon, and Slattery, Otolaryngologist, did an amazing job in shaving the tumor off his facial nerve yet leaving it intact and undamaged. Victor had a Baha implant at the same time knowing he would be deaf in the affected ear after the surgery. His audiologist at home, Dr DiSogra, was able to program the hearing device which was attached several months later. In addition to the deafness, Victor experienced extreme fatigue after the surgery. His doctor explained this to him by saying "consider yourself like a twin engine plane flying on one engine."

All things considered, Victor says he is “incredibly blessed and very lucky.” He has had the support of his wife, his family, and his friends throughout it all. He and Linda have always enjoyed traveling, having traveled to many places throughout Europe, Tahiti, the Orient and Australia. They are currently looking forward to a Mediterranean cruise this summer.

***Interview by Kristin Ingersoll***

*Editor’s Note:*

Victor Mankoski tells of having a “Baha” implant for single-sided deafness (SSD) at the time of his second surgery. The Baha system is manufactured by Cochlear Americas. A second bone anchored hearing system was FDA approved in August 2009, Oticon Medical’s “Pronto.” Both systems require minor surgery. And now we learn that another company, SonitusMedical, is currently developing a non-surgical “SoundBite” system for SSD that transmits sound via the teeth using an ITM (in the mouth) hearing device.



## **Spring Meeting**

### ***“Coping with the Aftermath of Acoustic Neuroma”***

#### ***An Informal Patients Panel & Discussion***

Our Panelists will discuss experiences with:

Balance Problems

Facial/Eye Problems

Tinnitus

Fatigue & Depression

Headache

**Sunday, April 18, 2010 1-3 PM**

Summit Medical Group, Lawrence Pavilion

One Diamond Hill Road

Berkeley Heights, NJ 07922

Q & A   Refreshments   Social Time

If you plan to attend the meeting, please RSVP to Wilma Ruskin at

[info@ananj.org](mailto:info@ananj.org) or 609-799-4442

## **Directions to Summit Medical Group, Berkeley Heights, NJ**

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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.