

ANA/NJ Newsletter

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Panel Discussion



From left to right: Pam Betteron, Nancy Bonnet, Irv Serkin, Joel Krause and Kristin Ingersoll

New ANA/NJ Board member John Rivers opened the meeting and introduced our five panelists. Kristin Ingersoll began by describing her 1997 middle fossa surgery for a 1.1 cm acoustic neuroma. Knowing what she does now, for such a small tumor she said she would probably wait-and-watch, but at the time the doctors were certain the surgery would be without complication. But it didn't happen that way, and she has spent the years since repairing facial/eye problems. There were various cosmetic surgeries and four trips to the University of Wisconsin for neuromuscular retraining with Jackie Diels. She joked that what she really wanted was to "get her pout back." Her husband, Joel, speaking next to address the family member perspective, emphasized how much he admired her perseverance through it all. His job, he thought, was mainly to be supportive. What bothered him mostly early on was learning that her eyesight could be in jeopardy. But that danger passed and at present he adjusts mainly to Kristin's hearing loss.

Irv Serkin described his experience over the past 5 years as a wait-and-watch patient with a 0.2 mm tumor. Perhaps the tumor has now grown to 0.3 mm (there's a difference of opinion about that), but Irv's major concern is a recent, severe attack of vertigo. He's worried there may be more and is considering having the tumor treated soon. Others at the meeting commented on their own bad experiences with vertigo.

Nancy Bonnet reported on her experience with the BAHA (bone anchored hearing appliance), adding to her recent interview information in the newsletter (May 2005). She stressed that anyone interested in BAHA should request a trial using Entific's "strong" simulator. She said getting insurance coverage could be a real chore, but one has to stick with it. Her final BAHA cost (\$18,000) was worth the effort. She repeated that the support she received from Dr. Kwartler and his staff was wonderful and extremely important.

Finally, Pam Betterton reported on her successful Gamma Knife treatment in April 2003 with Dr. Joseph Landolfi at JFK Medical Center. At first, Pam expected to go to New York, but then learned of the JFK center in Edison. Hearing loss, she said, appears to run in her family. But interestingly, her bad left ear was not the one with the tumor. Her right ear received the radiation treatment and she is doing well.

John Rivers closed the meeting on a happy note explaining how his own hospital experience taught him to be thankful his tumor was at least benign and treatable. He lost hearing in the left ear after translab surgery, but is managing quite well.

Celebrating Our 10th Anniversary! -- 1995-2005

Dear ANA/NJ Members and Friends,

I remember January 8, 1995... My letters of appeal had gone out on October 20, 1994, to approximately 100 New Jersey acoustic neuroma 'alumni' (as we called ourselves back then). The meeting was held at the home of Barbara Reed in East Brunswick, NJ. Twenty-six people met together that day, and decided that we wanted to continue to meet, as the New Jersey Chapter of the Acoustic Neuroma Association. We went around the room and introduced ourselves, and each shared a bit of our personal history, and why we were there. Several people talked about the isolation, and the feeling of being different; of not being "understood"; some were looking for solutions to the consequences of their surgery; many said it was a comfort to be among people who had similar experiences; some were there out of gratitude for being a survivor; some wanted to give something back...

We talked about our future as a group, and where our focus should be... We talked about where and when to meet, speakers, topics, committees, finances...

We left with the sense that we were part of something new and exciting...

So here we are, 10 years later, and still going strong! No longer a chapter of ANA, we are an independent, nonprofit organization, with an all-volunteer Executive Board and Medical Advisory Board. Today, although our focus has changed, and is directed more towards newly diagnosed patients than those with problems, we now have 170 members; a newsletter that is sent 4 times a year to more than 500 people in New Jersey and elsewhere; an often visited website; informative brochures; regional conferences, and ongoing projects that are designed to further awareness of acoustic neuroma and other cranial nerve tumors.

Thanks to all of you for your support and for being a part of ANA/NJ over the past 10 years. Our work continues....

Sincerely,

Wilma

The Road Less Traveled: My Experience with Gamma Knife

by
Nancy DePalo

On December 26, 2004, as my husband and I were heading to NYC to celebrate my birthday, I experienced an acute episode of vertigo. My family doctor diagnosed my condition the next day as labyrinthitis, an inner ear infection. He prescribed an antibiotic and various “bandaid” medications for dizziness. Although resolving, I continued to have serious equilibrium problems and a feeling of pressure in my left ear.

After a week I returned to work. A friend recommended an ear specialist and I scheduled an appointment immediately. After a gamut of tests proved inconclusive, the ear doctor suggested an MRI. I hesitated, but my mother, who was visiting at the time, persuaded me I had nothing to lose and she wanted to know what was wrong.

Four hours after the MRI, the ear doctor called me with news that shook my world. “You have a benign tumor in your ear called an acoustic neuroma, and you must see a specialist immediately,” he said. He gave me the names of two Skull Base centers, one on Long Island and one in NYC. I was stunned.

I began researching acoustic neuromas and found the websites filled with scary stories. I learned, too, that my friend’s sister had had a large AN removed and was left with facial paralysis and deafness because she ignored her symptoms and waited too long to seek treatment. Since I work at a hospital, I was also able to talk with surgeons, neurologists and audiologists. Finally, I learned more about my own particular case by meeting with a neurosurgical team on Long Island and one at Weill-Cornell Medical Center in NYC. Both teams explained that I had a 1.5cm tumor and, because it was located back by the brainstem, I was not experiencing some of the usual symptoms such as loss of hearing. Both teams recommended surgery. They felt that although I would likely sacrifice my hearing in the affected ear, they could probably preserve the facial nerve. Of course, the operation would be invasive brain surgery, which involved possible complications as well as a 6 to 8 week recuperation period. I left these consultations dazed. Should I undergo such a risky procedure?

A month prior to this, the Chief of Audiology Services at my hospital had given me a brochure from a Long Island hospital that offers Gamma Knife radiosurgery. He said: “You HAVE to do this. You are young, the tumor is small and they can preserve your hearing, most likely without damage to the facial nerve. Please check it out.” My surgeons advised against radiation treatment, but by then I had joined ANA and learned more about Gamma Knife. Through ANA, I was also able to speak with some wonderful AN patients who recommended the treatment over surgery. I decided on Gamma Knife for my treatment and to go to the University of Pittsburgh Medical Center because of its decades-long experience with this procedure.

From the beginning, I had confidence in the team at Pittsburgh headed by Dr Kondziolka. I sent my MRI and hearing records. Within two weeks I received a letter confirming that I was an excellent candidate for Gamma Knife. I was given a 98% chance of tumor growth control, a less than 1% risk of delayed facial weakness and a 50-60% chance of hearing preservation at the current high levels. The administrative coordinator at the center, Charlene Baker, handles everything from insurance paperwork to travel arrangements. I selected March 24 for my treatment.

On March 23 I met with the Gamma Knife team – a nurse, radiation oncologist and neurosurgeon-- to review my case and the Gamma Knife procedure, and promptly at 6 a.m. the next morning I reported for treatment. Loose-fitting clothing was permitted. Most everyone worries about the head frame, or “crown,” that must be attached to the skull to prevent movement during treatment. I won’t lie – it was the worst part of the entire procedure. It is uncomfortable and feels like your head is in a vice. However, it is not painful, just uncomfortable. And in the scheme of things, it is very minimal.

After the head frame was affixed and I had an MRI, I waited for about an hour while the team plotted how the Gamma Knife's 201 beams of radiation would converge on my tumor. The Gamma Knife itself looked like an old-fashioned hair dryer with pinpoint holes. They told me that I would have two sessions –one for 18 minutes and one for 14.

Before I knew it, the treatment was over. The head frame was removed and my RN placed Band-aids over the skin punctures on my head and a bandage around my head to de-pressurize it. I was told that, if I felt up to it, I could be discharged within the hour. My discharge instructions were:(1) no hair gel or spray etc. for 10 days;(2) Tylenol for any headache;(3) cold compresses for any swelling around the eyes resulting from the pain medication injected into my forehead; and (4) possible tiredness. An MRI and hearing test would have to be done after six months to determine the initial effects of the treatment. That was it! Believe it or not, by 1:30 p.m., I was having lunch in the hospital cafeteria, after which I walked the 4 blocks back to our motel.

For a week I had a mild headache (relieved by Tylenol), very puffy eyes (like a bad allergy attack) and I slept later than usual and took afternoon naps. Ten days later I returned to work. I had a significant sudden hearing loss in the affected ear four weeks after treatment. Pittsburgh prescribed a Prednisone taper pack and my hearing has partially returned.

I could not have gotten through all of this without the unbelievable support of family, friends, co-workers, ANA members and the Gamma Knife team. Never before have had I felt so much love. Everyone was thinking and praying for me in their own way and I truly knew this and carried it with me to Pittsburgh. I am sharing my step by step story here so that perhaps it will help others in their review of the treatment options available for acoustic neuroma.

(For any questions or more information, please contact Nancy at nld122753@aol.com.)

Please Note

Would you like to have your ENT or Family Physician receive a complimentary copy of the ANA/NJ newsletter? If yes, please contact Jane Huck at 908-725-0233 (Email JaneHuck@msn.com) and let her know the mailing address and whether or not you wish to have your name in the cover letter.

A Welcome Letter

“I thoroughly enjoyed the July 10 meeting. Not only did we socialize with old acquaintances, but we met new ones. As always, the program was terrific. This time we had a panel of our own members telling about their experiences with AN. The courage, spirit and knowledge they showed was unbelievable. I'm sure there were members who reevaluated their situations by the things they heard. Never do I come away from a meeting without learning something new and valuable. As a wait-and-watch patient, I'm grateful to the members who share their experiences. Between them and the doctors we have as speakers, I've been able to come to an educated decision as to what I'd do if I could no longer wait-and-watch.” (Phyllis Schreiber, July 12, 2005)

Help for Fatigue

Nancy Conn-Levin, MA, and Peter Black, MD, are the authors of a new patient guide, "Brain Tumors and Fatigue." Financial support for the project was provided by the Brain Science Foundation. For an online copy of the new guide, go to www.brain-sciencefoundation.org. For printed copies, email info@brainsciencefoundation.org

We are hopeful that Nancy will be our speaker at the April 30, 2006 meeting of ANA/NJ.

Acoustic Neuroma Sizes & Symptoms

Part 1

Our ANA/NJ Registry for the period 1995-2001 shows a decline in the average size of acoustic neuromas reported to us (Table 1). This is the good news and reflects mainly the improvement in diagnostic testing since the introduction of MRI in 1985.

Table 1

Year	No.	Average Size, cm
1995	13	2.22
1996	19	2.49
1997	22	2.13
1998	23	2.36
1999	21	2.25
2000	14	1.97
2001	18	1.85

The bad news, on the other hand, is that tumors 4.5 cm in size are included in the 2000 and 2001 series, and 5.0 cm tumors have been reported to us for both 2002 and 2004. This is not unique for NJ patients. As Dr. Samuel Selesnick and colleagues have observed in "The Changing Clinical Presentation of Acoustic Tumors in the MRI Era" (*Laryngoscope*, April 1993), "a significant number of patients are still being diagnosed with large tumors (>3 cm) despite the availability of technology capable of detecting tumors only several millimeters in size." Their survey of 126 AN patients at the University of California, San Francisco (1986-1990) found 16% of tumors undiagnosed until they reached 3.0 cm or over in size. Our own Registry data for 1984-2004 reveals exactly the same percentage (23 of 145 tumors at > 3.0 cm, or 16%).

The patients diagnosed with ANs >3.0 cm are most often the youngest in age. In the California study, the average age of patients with large tumors was 43 years; and for the 23 patients reporting large tumors for our Registry, the average age was 40 years. For comparison, the average age of 21 patients reporting small tumors (<1.0 cm) for our Registry was 56 years.

The time between first symptoms and initial diagnosis is significantly longer for patients found to have large tumors. The average time delay for the 145 patients in our Registry was 2.9 years, but for the 23 patients with tumors >3.0 cm, the average delay in diagnosis was 4.3 years. In some cases of large tumors, the duration of AN symptoms before diagnosis was 20 to 30 years.

Why do large tumors still go undetected for long periods of time? There are many possible reasons. Most annoying is the fact that an enlarging tumor might produce only very subtle symptoms that may be easily ignored by the patient. Dr. Selesnick speculates that this can be the case especially for younger patients, whose cranial nerves may also be better able to tolerate a growing tumor.

Misdiagnosis of early symptoms may also delay detection of the enlarging AN. Hearing loss, for example, which is one common symptom, might be attributed simply to aging and thought not to warrant the expense of an MRI. Less expensive audiometric testing, including the standard ABR (auditory brain-stem response) is still imperfect for identifying patients with acoustic neuromas. Only just recently has a modification in the ABR improved its ability to spot ANs when they are small. And the California study discovered that a surprisingly high number of patients with large tumors score quite well on the speech discrimination screening test. (See "Atypical Hearing Loss in Acoustic Neuroma Patients," *Laryngoscope*, April 2003)

The next issue of the newsletter will look at our Registry data for small (<1.0 cm) and medium (1-3.0 cm) ANs.

We are hopeful that Dr. Selesnick will be available to discuss "AN Sizes/Symptoms and Wait-and-Watch" at a future meeting of ANA/NJ

Cell Phones & Acoustic Neuroma

The National Brain Tumor Foundation's newsletter, *Search* (Spring, 2005), presents an article on "Cell Phone Use and Brain Tumors: Is There a Connection?" written by Stefan Lönn, PhD, a researcher at the Institute of Environmental Medicine, Karolinska Institute, Sweden. Dr. Lönn notes how the Swedish center for "Interphone Study" announced in March 2005 that there is evidence to support an increased risk of acoustic neuroma for persons using cell phones for 10 years or more. In April 2005, on the other hand, the Danish center for "Interphone Study" (there are 14 international centers in all) announced that there was no increased risk for persons using cell phones for 10 years or more. Both centers reported no increased risk for cell phone usage of less than 10 years. Both centers also found little evidence for a causal link between cell phones and other types of brain tumors. The twelve other centers for "Interphone Study" are expected to present their findings in 2006. Dr. Lönn concluded that study periods of more than ten years will be needed to resolve the question.

Meantime, for the same issue of *Search*, the National Brain Tumor Foundation (NBTA) asked several experts for their personal opinions regarding a possible correlation between cell phone use and the development of brain tumors. For the most part, the experts saw no reasonably proven association. Most interesting for acoustic neuroma patients is the statement by Patricia Buffler, PhD, Professor of Epidemiology at the University of California, Berkeley.

"To this point," she writes, "I consider the evidence of a causal link to be quite weak. For glioma and meningioma, available evidence is pretty consistently negative; that is, it points in the direction of cell phone use not causing these tumor types. One can argue that those studies were done too soon to detect an effect, but that does not mean that there is an effect.

"For acoustic neuroma, studies to date have been quite small. With small studies, one would expect results of different studies to vary due to chance. There are other issues bearing on interpretation. Acoustic neuromas do not always occur near the ear. In fact, they often occur closer to the cerebellum, which is deeper in the head. For deep tissue, exposure to radiofrequency radiation would be low, regardless of whether one used the cell phone on the left or right side of the head. However, the side of the head on which the tumor occurred would be related to hearing loss in the ear on that side of the head. Many acoustic neuromas grow slowly and can be present for a long time before coming to diagnosis. It could be that having difficulty hearing when talking on the phone on the side of the head on which the tumor occurred would lead one to go to the doctor, resulting in diagnosis of an acoustic neuroma that had been present for a while and been caused by something totally unrelated to cell phone use. This would introduce a spurious association between side of phone use and side of tumor."

Dr. Mitchel Berger, Chairman of the Department of Neurological Surgery at the University of California, San Francisco, is also doubtful regarding the possibility of finding a causal link. He writes: "I have been following this line of research for quite some time because of the public health concern and impact because of the widespread use. The literature has been consistently negative with a recent publication from the European funded study, the Interphone study, reconfirming this negative finding. In addition to the epidemiologic data, the animal studies do not indicate radiofrequency radiation increases risk."

Noticeably, the federal FDA's statement on risk straddles the fence, saying that the available evidence doesn't show any health problem, but that there is no absolute proof that cell phones are safe.

Special 10th Anniversary Meeting

"The Tinnitus Problem"

Dr. Scott Kay

Graduate of the University of Pennsylvania School of Medicine and board certified in otolaryngology, Dr Kay is an attending physician at the Princeton Medical Center

**October 16, 2005
1 PM Rooms A & B
Princeton Medical Center**

Discussion *Time to Renew Old Friendships!* Refreshments

Directions to the Medical Center

From Route 1: Take Washington Rd (Rt 571) to Nassau Street in Princeton. Turn left onto Nassau Street to Witherspoon Street, and turn right. The Medical Center is about ¾ of a mile on the right. For the parking garage, turn right on Henry Street just past the Medical Center building.

From northern NJ, Rt 287, Somerville: Take Rt 206 from Somerville to Princeton. Turn left onto Nassau Street and go to Witherspoon St. Turn left. Follow instructions above.

From northern NJ using the Turnpike: Take the NJ Turnpike south to Exit 8. Take Rt 571 into Princeton and Nassau Street. Follow instructions above for Rt 1.

From Pennsylvania: Take I-95 north across the Delaware R. and to the Princeton/Route 206 Exit. Take Rt 206 thro Lawrenceville to Nassau St in Princeton. Go to Witherspoon St and turn left. The Medical Center is on the right. For the parking garage, turn right on Henry St just past the Medical Center building.

**Conference Rooms A & B are down the hall on the left just past the
Information Desk**