

ANA/NJ Newsletter
Volume X, No. 1
January 2006

Meeting at Princeton Medical Center
October 16, 2005



Wilma Ruskin introduced our speaker, Dr. Scott Kay, otolaryngologist and attending physician at the Medical Center in Princeton. Dr Kay is a member of our Medical Advisory Board. Dr. Kay presented a thorough review of tinnitus types, causes and treatments. About 70% of acoustic neuroma patients, he said, have some problem with tinnitus; 60% develop tinnitus after their AN is treated; and for only 15% does the tinnitus go away after treatment for AN. He played examples of the types of noises patients have to put up with. Treating persistent cases is not easy because there are so many possible causes, such as problems in the hearing pathway (e.g., hair cells misfiring), brain sound mixups, musculo-skeletal problems (e.g., arthritis of the neck), psychological (stress, depression, fatigue, insomnia, sleep apnea), and troublesome medications (e.g., high doses of aspirin).

Dr. Kay said he was not a big fan of surgery as a form of treatment for tinnitus, nor did he think tranquilizers a good way to go, except for very severe cases. Neurontin, a medication for chronic, neuropathic pain, he thought could be helpful, even though somewhat tricky to regulate. Steroids are sometimes helpful. He spoke briefly about experimenting with vitamins, acupuncture, massage therapy or electrical stimulation. Dr. Kay was more inclined to recommend ways of masking bothersome sound, especially by what is called Tinnitus Retraining Therapy (TRT), whereby a patient's strong reaction to random tinnitus signals is gradually reduced. TRT, he noted, takes about 12 to 18 months of treatment, but is about 80% effective. The College of New Jersey in Trenton has a "Tinnitus Management Center." A lively discussion followed Dr. Kay's presentation.

Save the Dates!
ANA/NJ Meetings
are being planned for:

■ **February 19, 2006**
Sharing Experiences
(An Open Discussion)
1PM

■ **April 30, 2006**
1PM

(See future newsletters for details)

Annual Letter from Wilma

Dear ANA/NJ Members and Friends:

As 2005 draws to a close, let's take a look back at the past year ~

Meetings: *Our first meeting in 2005 was on April 3, at Overlook Hospital. Dr. Richard Hodosh, ANA/NJ Medical Advisory Board member and always a popular speaker, addressed dealing with regrowth. In July, we had a summer party and panel discussion at the Montgomery Center for the Arts, in Montgomery. Our panelists were Kristin Ingersoll (surgery), Joel Krause (Kristin's husband), Pam Betterton (FSR), Irv Serkin (Wait & Watch) and Nancy Bonner (BAHA recipient). The panelists talked about their personal acoustic neuroma experiences and answered many questions from the audience. The October 16 meeting, at the Medical Center at Princeton, was a celebration of ANA/NJ's Tenth Anniversary. Dr. Scott Kay, otolaryngologist and facial plastic surgeon as well as ANA/NJ Medical Advisory Board member, gave a lively presentation on tinnitus.*

Website: *Our web site has become a popular source of information for newly diagnosed patients. We have been averaging approximately 500 "hits" per month. Dave Belonger keeps the site up to date with current and future meeting information, new resources, links, patient stories, and a form for new patients to contact us. The ANA/NJ newsletter can also be accessed from the website (www.ananji.org).*

Literature: *Our brochures have been updated to reflect the latest information about treatment options, and about our organization.*

More News: *Our paid membership is currently 172, including 56 Life Members. We added 22 new members this year, including 3 new Life Members. The New Jersey Registry now contains 550 records, including 47 from out-of-state. Our mailing list now contains 480 names! Remember, no one is ever dropped from our mailing list unless they request it. Donations for the newsletter from non-members are always welcome.*

Looking ahead:

*The 2006 Directory will again be mailed free of charge to all active members in April. The Directory information letter and the 2006 Directory information form will be mailed in January. The Directory continues to be a very valuable tool for AN patients who have questions that can best be answered by another AN patient. **Please note that you must sign the release, and return the form to Jane Huck, to insure that your information will be included in the 2006 Directory.***

Our first meeting in 2006 will be on February 19, at the East Brunswick Library, in East Brunswick. Directions can be found on the web site and at the end of this newsletter. This will be an informal, “share and care” meeting -- always popular with our members. It’s a great opportunity to see old friends, to make new friends, and to ask the questions that only other acoustic neuroma patients can answer! Other meetings in 2006 are planned for April 30 and October 15. News about these meetings and other activities will be announced in newsletters and at www.ananj.org.

I am pleased to report that talks have begun between ANAUSA and our Board, with the goal of reestablishing a mutually beneficial relationship. As you know, difficulties over the past few years had caused a rift in our relationship, but with the advent of new leadership at the National office, possibilities exist Stay tuned!

We are currently compiling results from the recent questionnaire we sent to all of you, and the responses so far have been very positive and helpful. We hope to report the results either in the next newsletter or in a subsequent mailing.

Once again, I would like to thank all the members of our Executive Board, past and present, who have been so important in keeping our organization running over the years. Always, it has been a wonderful group of dedicated people. If you are interested in serving on the Board, please telephone me or send an e-mail, and we can chat about what’s involved. As you must know, adding new Board members from time to time is important for continuing and expanding our activities.

On behalf of the ANA/NJ Board, I wish you a happy and peaceful New Year.

Sincerely,

Wilma

Notices

ANA/NJ Survey

Please be sure to return your survey form to Dave Belonger. The ANA/NJ board members will be discussing returns at their January 22 and February 19 meetings.

BAHA System Update

Cochlear Americas, which recently acquired Entific Medical Systems, has announced that the BAHA system for Single Sided Deafness is now covered by Medicare. As an “implantable device,” the system is no longer included under the definition of hearing aids.

(Go to www.cochlear.com)

Presentation Videos Available

ANA/NJ Presentation Videos are available on VHS or DVD for \$10 each. To request a copy, please go to “Resources” on the ANA/NJ website, or contact Dave Belonger, 609-654-8141. Videos currently available are:

The Tinnitus Problem, Dr Kay (Oct 16, 2005)
AN Symptoms/Treatments, Members Panel (July 10, 2005)
AN Regrowth, Dr Hodosh (April 3, 2005)
Facial Reanimation & Restoration, Dr Winters (April 18, 2004)
Seminar on BAHA (Bone Anchored Hearing Appliance)

Declaration

We are pleased to note that Governor Richard Codey has declared the week of January 2-8 to be “Self-Help Support Group Week” in New Jersey.

NJ Brain Tumor Support Groups

In addition to ANA/NJ, other important brain tumor support groups in New Jersey are:

- The Central NJ Brain Tumor Support Group, meeting at St Luke’s RC Church, 300 Clinton Ave, N.Plainfield, NJ. For information, call 908-685-0917.
- The Monmouth/Ocean County Brain Tumor Support Group, meeting at Monmouth County Library, 2700 Allaire Rd, Wall, NJ. For information, call 609-758-0806, or email Nancy Conn-Levin at mngioma634@aol.com.

Panacea

Robert Hendrickson’s always fascinating *Encyclopedia of Word and Phrase Origins* (Checkmark Books, Third Edition, 2004) reminds us that Panacea, a daughter of Aesculapius, the Greek god of medicine, had the power to cure any ailment. Thus, “Over the years her name came to mean a cure-all, a panacea now being a remedy that will cure any problem, medical or otherwise.” (But just in case, there are support groups.)

Helen Walkinshaw in The Spotlight~



Helen Walkinshaw radiates such energy and enthusiasm when she speaks of her work as a field scientist with Bell Labs that it is hard to realize she has been retired since 1990. Although she is sitting, during our interview, in a wheel chair in front of two computers, it is as much to allow her to scoot around the room as anything else. Any physical deficits she is dealing with barely seem to slow her down, as her mind is obviously very dynamic and engaged. Her acoustic tumor seems to be barely a footnote although what led to her diagnosis certainly was not.

Helen loved spending days sailing with her colleagues from Bell Labs. On one such excursion 8 years ago, as they were coming in to Raritan Bay in rough water, Helen was suddenly violently seasick and experienced extreme vertigo. Her friends brought her home and put her to bed where she was too sick for several days to even get up to go to the doctor. When she finally did, she saw an ENT who ordered acoustic testing. He identified a one-sided hearing loss. She was then sent for an MRI, which revealed a 6 mm tumor. After that finding, Helen had annual MRI's for several years to monitor its growth. After 3 years, she developed an arrhythmia as a result of having hepatitis-C and viral myocarditis forty years earlier. Consequently, she had a pacemaker implanted that made further MRI's no longer possible. Over the 9 subsequent years her tumor has remained constant with no perceptible growth and her symptoms have remained unchanged. However, in the past 6-8 months she has had an increase in mild vertigo and thus had a CT scan prior to our visit. The good news is that the tumor appears unchanged, to the degree of certainty that the CT scan allows.

Helen grew up in Dunellen, NJ in a traditional suburban community. She was a self-described "brain" but was also always athletic, enjoying basketball, softball and tennis. She planned to go to college after high school but it was at the depth of the depression and WWII interfered with her plans. Instead she went to work at the British Ministry of Supply. She met many interesting people and advanced from stenographer to Executive Secretary. She naturally assumed statistical work for which she had a natural proclivity. At that time, women were prohibited from holding the job title of Staff Statistician. When the US got into the war, Helen joined the navy. She spent 5 years on active duty at what is now called The Naval Oceanographic Office outside Washington DC. This was a life-altering event. She was involved in research, and in writing and analyzing statistical reports. When the enemy surrendered she "went downtown" to work on a 20-year projective study of the Soviet potential and our political posture against their threat.

After her military service, Helen went to Douglass College and majored in Math with a strong physics emphasis. She continued on to graduate school at Rutgers where she studied theoretical statistics. This academic background supported by her experience in the military allowed her to be one of the first three women hired at Bell Labs. She went to work in the Undersea Research Department. It was a time of incredible creativity and innovation at Bell Labs. Helen traveled the world doing ocean experimental work and was the first woman from Bell Labs to do so. Their research was extremely formative, highly classified and yielded much in the way of original results. Most of it is still classified and is the basis of continuing undersea exploration. The unclassified areas include whale tracking and monitoring seismic noise.

Helen is an active member of the American Geophysical Union, Acoustical Society of America and the IEEE's Oceanographic Engineering Society. Recent years have found her working with colleagues to get their early research declassified and published, and they are beginning to have some successes. They are determined to make this Navy-Supported Oceanographic and Acoustic research available as a resource for graduate students since it was so formative to all that has come since. One gets the feeling that nothing can slow her down, although fate has tried to this past year.

In December of 2004, Helen was broadsided in her car by a delivery truck and suffered severe nerve damage. Just when she was getting back up to speed, she had an accident at a hospital and broke her femur, which was screwed together with a titanium plate. She also broke her wrist. She continues in physical therapy and walks with a cane or walker. Neither accident seems related to her vertigo or acoustic neuroma.

If at some time in the future Helen requires some type of procedure to control her acoustic neuroma she is likely to research and consider some type of radiosurgery. In the meantime, she has work to do.

Interview by Kristin Ingersoll

Acoustic Neuroma Sizes & Symptoms

Part II

Table 2 below shows sizes and symptoms of acoustic neuromas at the time of diagnosis as reported by 146 patients for our ANA/NJ Registry. You can scan the columns and compare the types and percentages of symptoms for the small, medium and large ANs.

Fourteen percent of the 146 tumors reported were small (< 1cm), 70% medium (1-3cm) and 16% large (>3cm). The average tumor size for the <1cm group was 0.7cm; 1.6cm for the 1-3cm group; and 4.3cm for >3cm. Average patient age at time of diagnosis was 56 (<1cm), 51 (1-3cm) and 40 (>3cm). The average delay between first symptoms and diagnosis was 3.1 yrs (<1cm), 2.5 yrs (1-3cm) and 4.3 yrs (>3cm).

Table 2
Reported Symptoms of Acoustic Neuroma
146 Patients, 1984-2004

Symptoms	All Tumors (146)		< 1 cm (21)		1-3 cm (102)		>3cm (23)	
	No.	%	No.	%	No.	%	No.	%
Hearing Loss	97	66%	12	57%	69	68%	16	69%
Ear Fullness	17	12%	3	14%	13	13%	-	-
Tinnitus	52	36%	11	52%	39	38%	2	8%
Vertigo	16	11%	4	19%	9	9%	2	8%
Nausea	6	4%	2	9%	4	4%	-	-
Dizziness	23	16%	3	14%	17	17%	3	13%
Imbalance	46	32%	6	28%	31	30%	9	39%
Headache	20	14%	1	4%	14	14%	5	21%
Earache	2	1%	-	-	2	2%	-	-
Fatigue	4	2%	1	4%	2	2%	1	4%
Facial Pain	3	2%	-	-	3	3%	-	-
Facial Numbness	15	10%	1	4%	8	8%	7	30%
Vision Problem	5	3%	-	-	1	1%	4	17%
Change in Taste	4	2%	1	4%	2	2%	1	4%
Slurred Speech	2	1%	-	-	-	-	2	8%
Hand Weakness	1	.06%	-	-	-	-	1	4%
Drooling	1	.06%	-	-	-	-	1	4%
None	4	2%	1	4%	3	3%	-	-

Part I of this article focused mainly on tumors over 3.0 cm in diameter. Close similarities for tumor size, patient age and delayed diagnosis were noted between ANA/NJ records and data reported by Dr. Selesnick and colleagues in “The Changing Clinical Presentation of Acoustic Tumors in the MRI Era.” Our Registry records also support this study’s finding that “The incidence of hearing loss, dysequilibrium [imbalance], headache, facial numbness, and diplopia [vision problems] all increased with increasing tumor size, while the incidence of vertigo decreased.” Tinnitus, on the other hand, was much less reported as an initial symptom for large tumors in our series (8% vs 52%), although for all tumors the percentage (36%) was the same.

The greater frequency of vertigo as an initial symptom for small tumors (<1cm) is noteworthy. As tumor size increases, vertigo as a symptom apparently gives way before a higher incidence of dysequilibrium (imbalance). Dr. Selesnick comments that acute vertigo may actually be seen as a “propitious symptom” in patients with small ANs, since it will cause these patients to seek medical care leading to early diagnosis. The two other main symptoms of small tumors, hearing loss and tinnitus, would be easier for patients to ignore. As with large tumors, patients with small ANs have faced long-term delayed diagnosis. One patient in our Registry had symptoms for 28 years before being diagnosed at age 70 with a 0.7cm tumor. Her initial symptoms in 1970 were hearing loss, tinnitus and headaches, and about ten years later, vertigo, imbalance and severe headaches. The small tumor was not identified until 1998. This patient is now “wait-and-watch” and has had ten MRIs since diagnosis.

Twenty-nine patients who reported with small tumors for our Registry are currently “wait-and-watch.” Data for 16 of the 29 is shown in Table 3. The average tumor size for this group is 1.0cm (range 0.2 – 2.0cm). These patients have been monitoring their tumors for an average of seven years (range 3 – 13 yrs). As seen in Table 3, hearing loss, tinnitus and vertigo are the three most common symptoms.

Table 3
Reported Symptoms of Acoustic Neuroma
16 Wait-and-Watch Patients
(1993-2002)

Symptoms	All Tumors (16)		< 1.0 cm (7)		1-2 cm (9)	
	No.	%	No.	%	No.	%
Hearing Loss	10	62%	3	43%	7	77%
Ear Fullness	2	12%	-	-	2	22%
Tinnitus	8	50%	4	57%	4	44%
Vertigo	6	38%	4	57%	2	22%
Nausea	2	12%	1	14%	1	11%
Dizziness	2	12%	1	14%	1	11%
Imbalance	3	19%	2	28%	1	11%
Headache	2	12%	1	14%	1	11%
Facial pain	1	6%	-	-	1	11%
None	1	6%	1	14%	-	-

There’s a lot of difference between living without knowing you have a large AN, and living knowing you have a small AN that may or may not be enlarging. The latter condition must surely be preferable, even if more anxiety-producing. In any case, at the ANA’s June 2005 symposium in Florida, doctors on the panel for advising pre-treatment patients recommended that “wait-and-watch” should include periodic MRIs (probably at least yearly, since some ANs have growth “spurts”) as well as periodic audiometric testing for speech discrimination (since hearing may

deteriorate even though an MRI scan may show no growth). Using the same, high quality MRI machine for every scan was also recommended. Given the risks involved with any treatment, and the well-known slow rate of growth of most ANs (1-2mm/yr), the panelists were inclined to recommend taking no action in cases of very small tumors, e.g., a tumor 0.5cm in diameter. There seemed to be consensus that, especially for younger patients, the time to “do something” would probably be (1) when the tumor was over 1.0cm and showed a tendency for further growth; and/or (2) when speech discrimination scores showed progressive deterioration in hearing; and/or (3) when quality of life became unacceptable. When the decision is to “do something,” at that time careful comparison of the benefits vs. risks of different types of treatment becomes the important calculation

The article by Dr. Selesnick & colleagues offers a general chronology of symptoms encountered at four stages of acoustic neuroma growth. Of particular interest for “wait-and-watch” patients would be the description of the first two stages. The authors write: “The intracanalicular stage is typified by hearing loss, tinnitus, and vertigo. In the cisternal stage the tumor involves the cerebellopontine angle cistern and is typified by worsening auditory symptoms, a transition from vertigo to dysequilibrium, and by headache due to localized dural irritation.” The authors stress the importance of diagnosis of an AN during the intracanalicular stage. They calculate that if a tumor diagnosed at this early stage were to continue to grow at the average rate, it would take between 1.5 and 2 years for it to reach the more critical cisternal stage. The authors caution that although general trends of this sort may be discerned, much variability exists. Most atypical would be tumors that are completely asymptomatic. Four patients in our series were entirely without symptoms: tumor sizes (cm.) were 0.4, 2.0, 2.5, and 2.5. The cautionary statement in the ANA’s 1987 booklet, *Acoustic Neuroma*, is still valid: “There is not a typical pattern of symptoms caused by a developing acoustic neuroma, thus making early diagnosis a challenge.”

Meeting

A Meeting for Sharing Experiences - Open Discussion -

February 19, 2006

1:30 PM

East Brunswick Public Library

2 Jean Walling Civic Center

East Brunswick, NJ 08816

(732)390-6950

A Time to Help Others

Make new Friends

Refreshments

Directions to the East Brunswick Public Library

From the North: NJ Turnpike to Exit 9, bear left to Rt 18 South. Go about 4 miles to **Rues Lane** (turnoff on right just past Brunswick Square Mall/Macy’s). Turn right onto Rues Lane and go to 4th traffic light. Turn left onto Civic Center Drive to Library parking lot #2 or 3.

Continued on next page

From the North: Route 287 South to Exit 9 (Bound Brook/Highland Park). Right onto River Rd, follow sign for Highland Park. Go 3..5 mi to 5th light. Turn right (sign says 18 South, George St,New Brunswick) over bridge onto **Rt 18 South**. Watch carefully for right turn onto **Rt 1 South**.

Take Rt 1 South to Exit marked "**Milltown,East Brunswick**" for Ryders Lane. Take Ryders Lane 4.5 mi to 9th traffic light and turn right onto Civic Center Drive. Park as above.

From the South: NJ Turnpike to Exit 8A. After toll, right on Forsgate Dr (Rt 32) to traffic light. Go right and North on **Rt 535** (Cranbury Rd) about 7 mi to traffic light at **Ryders Lane**. Go left on Ryders Lane, and left at the first traffic light onto Civic Center Drive. Park as above.

From the South: Garden State Parkway to Exit 105. Take Rt 18 North (Exit marked "New Brunswick"). Take **Rt 18 North** several miles to heavily commercialized area. Watch for sign to **Rues Lane**. Bear right at jughandle to cross Rt 18. Follow Rues Lane to 4th light, and turn left onto Civic Center Drive. Park as above.

(In the Library, the meeting room is on the main floor. Walk to the back on the left.)

