

**Chapter Meeting, Lawrenceville,
March 25, 2012**

Our Spring chapter meeting this year was a “Time to Share” open discussion session for AN patients, family and friends held at the Lawrenceville Branch of the Mercer County Library System, March 25, 2012. The library facility was excellent for our purposes. Twenty-seven people attended the session. Wilma Ruskin welcomed all and Dave Belonger presided.

The rapid to and fro of a fast moving open discussion such as this is difficult to summarize. But it was most noticeable (as during our October 23 meeting) that patients were reporting mainly on small tumors



in the 6 to 10 mm range. And for this reason there was much interest in the wait-and-watch treatment option, and considerable concern over learning that serial imaging to monitor tumor growth during wait-and-watch was not always a safeguard for hearing preservation. That is, even though serial imaging might show no tumor growth, hearing loss could still occur. The discussion then shifted to other treatment

options -- the middle fossa surgery approach, single session radiosurgery (Gamma Knife) and fractionated radiotherapy – still all mainly with hearing preservation in mind. Wilma called attention to ANA/NJ’s planned mini-conference for October 28 when doctors for each of the treatment options will be present to address this concern.



Some other important matters for consideration during the meeting were: a case of difficulty with speech following surgery; experiences (3 separate cases) with facial numbness during wait-and-watch; an unusual instance of bilateral tumors; a bad experience with closed MRI; a good experience with middle fossa surgery for a 8mm tumor by a young woman patient who wanted treatment while young and returned to work only two weeks after surgery.

Thanks to all for sharing and for helping to make this a most rewarding meeting.

Notices

• The ANA/NJ Mini-Conference at JFK on October 28 (see below, p. 7) presents an excellent opportunity to learn more about treatment options and outcomes, new technologies and rehabilitation processes for acoustic neuroma. Here’s a chance to ask your important questions and participate in open discussions with medical professionals and chat with other AN patients having similar concerns and/or prior first-hand experience. There’s always a special camaraderie at these meetings of acoustic neuroma patients, family members and friends. Any last minute question about the conference? Give Wilma Ruskin or Jane Huck a call.

- Among the several booklets published by the Acoustic Neuroma Association is *Improving Balance Following Treatment for Acoustic Neuroma* (2004), 12pp. A free copy is available by contacting the national office at 770-205-8211 or email localgroups@anausa.org.
- Speaking on “What’s New in Research” at the June 2011 ANA Symposium in Cincinnati, Dr. Andrew Parsa (UCSF) presented an explanation for why some wait-and-watch patients have experienced hearing loss in spite of no tumor growth showing up during serial imaging by MRI. Perhaps, said Dr. Parsa, small tumors close to the cochlear nerve may have developed undetected micro-hemorrhages with scarring that compress and compromise the cochlear nerve. Special MRI studies are under way at UCSF to investigate this hypothesis.
- *The Healthcare Blue Book* is an online “Free Guide to Fair Healthcare Pricing.” (www.healthcarebluebook.com) The website search engine provides information for hospital, clinic and doctor charges for specific medications and procedures.
- The development of bone anchored hearing systems continues. AN patients interested in investigating implantable systems online can compare Oticon Medical’s “Ponto Pro” system, reviewed at www.oticonmedical.com, and Cochlear’s “Baha 3” system, reviewed at www.cochlearamericas.com.

“Choosing Wisely”

“Choosing Wisely” is the name of the current national campaign by medical organizations in the U.S. aimed at encouraging physicians to cut back on ordering unnecessary tests and procedures that don’t benefit patients and in some cases may actually be harmful to them. The initiative traces back to an article in *The New England Journal of Medicine* (vol. 362, Jan 2010) entitled “Medicine’s Ethical Responsibility for Health Care Reform – The Top Five List,” by Dr. Howard Brody. Dr. Brody, a medical ethicist, challenged medical specialty societies to identify diagnostic tests or treatments “that have been shown by the currently available evidence not to provide any meaningful benefit to at least some major categories of patients for whom they are commonly ordered.” Thus far, nine medical specialty societies, including the American College of Physicians, the American College of Cardiology, and the American Academy of Family Physicians, have each developed ‘Top 5’ lists of overused tests and treatments.¹ Two societies that plan to publish their lists later in 2012 are the Society of Nuclear Medicine and the American Academy of Otolaryngology – Head & Neck Surgery. Much quoted in news releases about the campaign is a Congressional Budget Office advisory that as much as 30% of health care provided by the U.S. is squandered on unnecessary tests, procedures, hospital stays and other services. Dr. Glen Stream, president of the American Academy of Family Physicians, states: “[Our] ‘Top 5’ list encourages more in-depth conversations between patients and their doctors so they discuss all options and then ‘choose wisely’ when it comes to a treatment plan.”² The American College of Radiology’s list asks for doctor-patient discussion of the worthwhileness of “imaging for uncomplicated [i.e., non-specific] headaches.” Dr. Christine Cassel, president of the American Board of Internal Medicine, has cautioned: “We aren’t saying you should never do it – these are times you ought to have a conversation about whether you need it or

not.” In other words, for the medical societies, “Choosing Wisely” is about good judgment, not curtailing care.³

¹ For current lists, see www.choosingwisely.com.

² See www.aafp.org, News Now (4/16/2012); also, “When to Say ‘Whoa!’ to Your Doctor,” in *Consumer Reports*, June 2012.

³ See www.amednews (4/16/2012).

Diagnosis of Acoustic Neuroma

Doctors in the departments of otorhinolaryngology at two hospitals in Finland recently collaborated to study the impact of “Diagnostic Delays in Vestibular Schwannoma” in the era of magnetic resonance imaging (MRI).⁴ The study focused on 59 acoustic neuroma patients (1992-2006) with sufficient primary health care data from the time of symptom onset to allow accurate analysis of diagnostic delay. Nine patients diagnosed with acoustic neuroma incidentally were therefore not included in the study. Since the median delays in diagnosis finally used in the study were actually remarkably short (Table II), the study concluded unsurprisingly that “prolonged” delays in diagnosis in the MRI era “do not appear to significantly affect tumor size or patient morbidity.” This was the main conclusion. More interesting (and striking) was the observation made in the commentary that “it is questionable whether vestibular schwannoma patients benefit or suffer from early diagnosis.” On the one hand, the researchers observed, early diagnosis of small tumors and the ‘watchful waiting’ approach have shown that “a considerable number of tumors remain small for a long time and do not require active treatment.” On the other hand, early diagnosis of small tumors can result in early treatment, which “may well represent a worse option than delayed diagnosis, in terms of future life quality.” We saw a connection here with “Choosing Wisely,” examined above.

Tinnitus Treatments

The Better Hearing Institute has made available the results of a 2008 survey “The Prevalence of Tinnitus in the United States and the Self-reported Efficacy of Various Treatments.” (www.betterhearing.com) Subjects with tinnitus were asked to indicate (1) which of 9 treatment methods they had tried, and (2) how beneficial the method was on a scale of 0-100%.

⁴ H. Teppo et al, *Journal of Laryngology & Otology*, vol. 123 (2009), 289-293. Full text of the article is made available at www.ANAUSA.org.

For the treatment methods tried, the 3,473 respondents indicated:

<u>Method</u>	<u>% Tried</u>
Herbs/dietary supplements	6.8
Hearing aids	6.1
Professional counseling	5.9
Medication from physician	4.8
Relaxation techniques	3.5
Music	3.4
Psychological counseling	1.2
Non-wearable sound generator	1.2
Wearable sound generator	1.0

As for which of these treatment were selected as most beneficial, the highest median ratings were found for: Hearing aids (34%), Music (30%), Relaxation techniques (10%).

The authors of the survey puzzled over these findings (as do we). Why do herbs and dietary supplements, although not rated highly in benefits, appear as the most common choice? Why did so many participants in the survey not try hearing aids as a treatment method, although the survey showed 30% of aid users had moderate to substantial benefit? And why did so few of the respondents try sound generators, even though clinical experience has shown the benefit of these devices? The authors observe that only a small number of people actually seek help for their tinnitus. They write: “The reason perhaps lies in the widespread belief that tinnitus is incurable or untreatable.” Perhaps this is a basic answer to the questions raised by the survey?

Acoustic Neuroma Sizes, 2002-2011

The average maximum diameter sizes for acoustic neuromas reported for the ANA/NJ Registry for the years 2002 to 2011 are shown in the following table:

Year	No.	Average Size,cm
2002	9	2.30
2003	6	1.77
2004	4	2.35
2005	6	1.85
2006	4	2.40
2007	8	1.71
2008	7	2.06
2009	8	2.31
2010	6	2.07
2011	4	1.60

The overall average size of the 62 tumors reported for 2002-2011 is 2.04 cm. This is a little less than the 2.18 cm calculated for the 130 tumors reported earlier for the Registry for the period 1995-2001.⁵ This is not to imply that larger ANs in the range of, say, 3.5-5.0 cm have stopped being reported. For the year 2004 in the table above, for example, the four tumor sizes were 0.6, 1.8, 2.0 and 5.0 cm, giving the average of 2.35. And the 59 ANs studied for the article on p.3, for example, had an overall average size of 1.8 cm, but the range was 0.3-4.2 cm; and “among patients with four or more presenting symptoms, the mean tumor diameter was 3.3 cm, versus 1.8 cm among the rest of the patients.” So doing averages tends to mask the inclusion of large tumors. In the MRI era, it’s not a lack of large ANs but the increasing number of smaller ANs being discovered that’s driving downward the overall average size. It looks like more and more patient-doctor conversations about whether or not to treat small acoustic neuromas can be anticipated. Already in some European countries having a National Health Service social costs appear to be deciding in favor of ‘watchful waiting.’

⁵ See “Acoustic Neuroma Sizes & Symptoms,” in ANA/NJ Newsletter (Sept 2005 & Jan 2006).

Tinnitus Research at the University of Buffalo (SUNY)

Our October 2011 newsletter called attention to Dr. Richard Wiet’s encouraging forecast for tinnitus sufferers at the ANA Symposium, June 2011: “Hold on,” he said -- new treatments are on the way. This same optimism was voiced by University of Buffalo (UB) researchers Brian Allman and Edward Lobarinas in their review of the proceedings of the Fifth International Tinnitus Research Initiative (TRI) Conference hosted at the UB Center for Hearing & Deafness, August 19-21, 2011: “People with tinnitus,” they wrote, “can rest assured that scientists and clinicians are hard at work to bring the promises of tomorrow’s treatments closer than ever before.” The review noted how the UB conference had brought together the most prominent clinical and scientific experts on tinnitus from around the world. “The neuroscience focused lectures showed that major advances in neuro-imaging have begun to reveal the complex neural network involved with tinnitus. Other studies revealed that complex interactions exist between auditory centers in the brain and non-auditory centers such as the amygdala, pre-frontal cortex and hippocampus, which are areas that are believed to play a part in the emotional and psychological aspects of tinnitus. . . . Several clinical and basic science presentations described the efficacy of treating tinnitus and hyperacusis with a variety of approaches ranging from electrical stimulation to new drug therapies, and customized sound therapies to counseling. The clinical talks received considerable attention and several of these presentations were standing room only.”⁶

The achievement of the UB Center for Hearing and Deafness and its leadership in the field of tinnitus research is most likely already known to many tinnitus patients. The center’s website, like that of the American Tinnitus Association, is a key place to go for learning about progress in the field.



Richard J. Salvi, Ph.D., the director of the center, who was recently named a Distinguished Professor of the State University of New York (SUNY), is considered a pioneer in research on hearing and deafness. “[Dr. Salvi’s] main area of research is the auditory physiology associated with acquired hearing loss. He has studied noise and ototoxic drug-induced hearing loss, tinnitus, inner-ear physiology, central auditory plasticity and reorganization, hair-cell regeneration and. . . the use of stem cells to treat hearing loss.” Currently, mainly with funding by the National Institute on Deafness & Other Communication Disorders (NIH), he is working on Neural

Aspects of Tinnitus to identify changes that occur in the auditory cortex in animal models with behavioral evidence of tinnitus, and to evaluate drug therapies to suppress tinnitus.

The primary mission of the Center for Hearing and Deafness is to conduct research. The center encourages an interdisciplinary approach to problem solving. Among Dr. Salvi's many colleagues at UB are Brian Allman, studying Auditory Cortex Plasticity and Tinnitus; Edward Lobarinas, who is investigating Functional Hearing Related to Inner Hair Cell Loss; and Alan Lockwood, who is using Positron Emission Tomography (PET) for studies of neural activity related to tinnitus.

Interestingly, tinnitus research at the center has been advanced in recent years by the U.S. Army and Office of Naval Research. The review of the TRI Conference observes how tinnitus has been a major problem among military veterans: "At the end of 2004, annual compensation payments to veterans with tinnitus as their major disability were nearly \$190 million."

The UB website (www.buffalo.edu) provides a list of valuable internet links for tinnitus patients.

⁶ See "Fifth International TRI Conference: Perspectives and Reflections," *Tinnitus Today* (Winter 2011), at www.buffalo.edu/news.

Did Daniel Boone (1734-1820) have an Acoustic Neuroma?

We will never know for certain. In Boone's lifetime the disease was still essentially unknown. Post-mortem sightings of what were probably acoustic neuromas began to be made as early as 1777, and the symptomatology was being described in the 1830s. Only in the last decades of the 19th century, however, did study of brain anatomy make possible somewhat accurate localizations of acoustic tumors, correlated with symptoms. In the earliest attempted surgery for AN in 1890, the patient died before the tumor could be localized. The first successful surgery for AN was performed in London in 1894. Still, cranial surgery remained a very risky venture; the mortality rate at the beginning of the 20th century was between 68 and 86%. The first microsurgery for AN was performed in the United States by Dr. House in 1961.

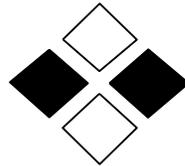
Boone was 86 years old when he died in 1820, presumably of a heart attack. There was no autopsy. Boone had been suffering since the 1790s from recurrent, severe rheumatoid arthritis, which he medicated with liberal doses of calomel (mercurous chloride), a popular but poisonous 'cure-all' of the time. His hearing and eyesight were failing and his memory of recent events was impaired. He could no longer go on the 'long hunt.' He said he was 'worn out.' At the end, as his biographers all record, he complained of "an acute burning sensation, such as he had never before felt, in his breast, which continually grew worse." The remains of the famous frontiersman are buried in Frankfort, Kentucky.

We need to take into account that average life expectancy around 1800 was about 35 years and that the still mainly east coast population of the emerging United States was then only about 5 million. Cases of acoustic neuroma must have been extremely rare. What early Americans knew and worried about were the infectious diseases, the great killers, like smallpox, diphtheria, measles, cholera, dysentery, malaria, tuberculosis. To have lived as long as he did, Boone was fortunate to have survived his own childhood bout of smallpox. Subsequent to that, his preference for living apart from human settlements, his constant urge to "Go West," probably contributed to his longevity. We might say Boone practiced an early form of preventive care.

Some References: T.G. Machinis et al, "History of Acoustic Neuroma Surgery," *Neurosurgical Focus*, Vol 18 (2005); Michael Lofaro, *Daniel Boone: An American Life* (2003); David Dary, *Frontier Medicine* (2008).

**Top 10 from the Medical Records,
As Dictated by Physicians**

1. The patient is tearful and crying constantly. Also appears to be depressed.
2. Numb from the toes down.
3. The patient has chest pain if she lies on her side for over a year.
4. No past histories of suicides.
5. Occasional, constant, infrequent head-aches.
6. The patient has left his white blood cells at another hospital.
7. On the second day the knee was better, on the third it had disappeared completely.
8. The patient refused an autopsy.
9. Patient was released to outpatient department without dressing.
10. Discharge status: Alive but without permission.



ANA/NJ Mini-Conference

Acoustic Neuroma: Before and After

Sunday, October 28, 2012 9:30 a.m. – 3:30 p.m.
The Conference Center
JFK Medical Center
65 James Street, Edison, NJ

Program

Registration & Coffee

9:30-10:30

Welcome by Wilma Ruskin, President ANA/NJ	
Welcome by Dr. Joseph C. Landolfi, NJ Neuroscience Institute, JFK	10:30
Doctors' Panel: Acoustic Neuroma – Diagnosis & Treatment Options	10:45-12:30
<ul style="list-style-type: none"> • Dr. Richard M. Hodosh, Wait-and-Watch • Dr. James K. Liu, Surgery Approaches • Dr. John D. Lipani, CyberKnife Fractionated Radiotherapy • Dr. Joseph C. Landolfi, Gamma Knife Radiosurgery 	
Lunch	12:30-1:15
Keynote Address: “Visual Vestibular Mismatch Syndrome”	1:30-2:30
<ul style="list-style-type: none"> • Dr. Michael L. Rosenberg, NJ Neuroscience Institute, JFK 	
Workshops	2:30-3:30
<ul style="list-style-type: none"> • Joshua David O’Brien, “Meditation for Tinnitus & Stress” • Elizabeth Cook, “Advances in Hearing Technology” 	

Directions to JFK Conference Center

From Philadelphia & south. Take the NJ Turnpike North to Exit 10 to **Route 1 North**. On Route 1 North, at the Menlo Park Mall, exit on the right to go around the jughandle onto **Parsonage Road**. Continue on Parsonage Road past the mall and on through the underpass to the traffic light at **Route 27** (landmark there is the Dunkin Donuts). Go straight across Route 27. Parsonage Rd now becomes **James Street**, and the JFK Medical Center main entrance and ample parking will be seen on the left. But note that the **Conference Center** is just opposite on the other side of James Street. Turn right for the Conference Center and its separate parking area.

From Newark & north. Take the Garden State Parkway South to Exit 131. Make a right off the exit onto Route 27. Continue south on Route 27 to the traffic light at James Street (Dunkin Donuts on the right) and turn right onto James Street. The JFK Medical Center main entrance and parking will be on the left, but, as noted above, the Conference Center and its parking area will be on the opposite side of James Street. Turn right into the parking area for the Conference Center.

