

ANA/NJ Newsletter
Vol. X, No. 4, January 2007

Annual Letter from Wilma

Dear ANA/NJ Members and Friends ~

Happy New Year! As we begin our 11th year, I would like to reflect on the eventful year just ended. First of all, a major change in 2006 was our reconnection with ANA. We are once again a local chapter of the national organization. ANA's mail notice for our October 22 meeting, which brought a good attendance, was one benefit of this renewed affiliation.

Here is a recap of the past year's activities:

Meetings: On February 19, we met at the E.Brunswick Library for an always popular "Share and Care" session. The April 30th meeting was at JFK Medical Center in Edison with speaker Nancy Conn-Levin, whose topic "Rediscovering Joy and Humor" was very inspiring and encouraging for the many who attended. Finally, on October 22, Dr. Samuel Selesnick from Cornell Weill Medical College in NYC spoke about "Acoustic Neuroma: Diagnosis and Watch-and-Wait." A popular, returning speaker, Dr. Selesnick accepted membership this year on our Medical Advisory Board.

Website: Our website, www.ananj.org, is maintained and up-dated regularly by Dave Belonger. It continues to be a wonderful source of patient information, resources, links to other organizations, current ANA/NJ projects, patient stories, newsletter articles meeting notices, and a contact for patients to fill out and return to us with their questions. This year alone, we received inquiries from 20+ newly diagnosed patients via the contact page.

More News: Our paid membership, including Life Members, is 180, with 27 new members this year and two new Life members. Our New Jersey Registry now contains 560 records, including 50 from out-of-state. Our mailing list currently contains 465 names. Although our policy has always been never to drop anyone from the list unless requested to do so, the rising costs of printing and postage have made it necessary recently to poll some members to verify mailing and email addresses, and to find out who would like to remain on the list. If you were not part of our recent poll, but no longer wish to receive the newsletter, or if you would be happy to view the newsletter at the website, please let us know. The money we save can be put to good use for other services to our members.

Looking ahead:

The ANA/NJ 2007 Directory will be mailed to all active members in April. The Directory information letter and the 2007 Directory information form will be mailed in January. The Directory continues to be a very valuable tool perhaps especially for recently diagnosed AN patients who have questions that can best be answered by other AN patients.

Our first meeting for the New Year will be a "Share and Care" meeting, hosted by new Board member, Jon Bonesteel. It will be held in Montclair, NJ on Sunday, February 4, at 2:00 PM. Directions and other information can be found in the newsletter and on the website. An April 29 meeting at Morristown Memorial Hospital will feature audiologist Liz Cook, a popular speaker for ANA/NJ.

The International RadioSurgery Association survey of radiosurgery patients is soon to become a reality. Co-sponsored by IRSA, the radiosurgery centers of the Universities of Pittsburgh and Virginia, and ANA/NJ this will be the first major study of AN radiation patients looking at "quality of life" issues. We will be asking for your participation in the survey.

Another project we will be working on is making our organization better known to area doctors so that they may refer patients to us. If you would like to add your doctor to the list, please let us know.

Once again, I would like to thank just a few of the special people who keep our organization running. First of all, to Jane Huck, who serves as Treasurer, Membership Chairperson, and Directory Editor. In addition, Jane stamps, labels, and mails 462 copies of the newsletter, 3 times a year! To Kristin Ingersoll, for her thoughtful and insightful *SPOTLIGHT* interviews for the newsletter. To Dick Barker, for his consistently excellent editing of our newsletter, which includes gathering information and writing articles. Dick is also responsible for maintaining the New Jersey Registry of acoustic neuroma patients. Many thanks as well to Dave Belonger, who maintains our website, and who took on the onerous job of coordinating contacts with the people on our mailing list for our recent poll. And finally, to Phyllis

Schreiber and Kathie Belonger, with help from Jeane and Andy Gregg, who provided the speakers, locations and refreshments for our statewide meetings.

On behalf of the Executive Board of ANA/NJ, I would like to thank all of you who have written, called, e-mailed, or sent donations to express your support. We look forward to your continued support, and we hope to see you at the meetings in 2007.

Sincerely,

Wilma

Chapter Meeting at Morristown Memorial Hospital October 22, 2006

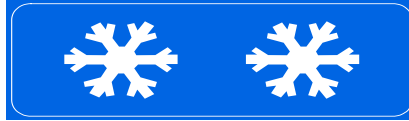
Our speaker was Dr. Samuel Selesnick, Weill Medical College of Cornell University, 520 E. 70th St., New York, NY 10021 (212-746-2282).



Dr. Selesnick's topic was "Acoustic Neuroma: Size, Symptoms, Watch-and-Wait." About 35 people attended the meeting. There was a lively Q&A period.

Dr. Selesnick discussed treatments currently available for AN (wait-and-watch, microsurgery, radiosurgery/radiotherapy) and various factors influencing choice of treatment (size and location of tumor, symptoms, tumor growth rates, and age and overall health of patient). He made clear that deciding on the best option is not always easy or certain. Selecting wait-and-watch for small tumors, for example, can be problematic because of unpredictabilities in the rates of tumor growth. Small tumors would still need to be monitored regularly with MRI. For microsurgery, it may be true in general that small tumors are easiest to remove (sometimes, said Dr. Selesnick, it's like you say "hand's up" and the bad guys come out without a fight), but the battle for removal of small tumors can also be long and outcomes discouraging. Radiosurgery or radiotherapy are other choices, but patients must be reminded that the goal of radiation treatment is to stop tumor growth – not remove the tumor. This is sometimes not acceptable for younger patients especially. Irradiated tumors may in fact swell a bit before shrinking, which can cause patient anxiety. Dr. Selesnick said he tends to favor surgical intervention for young patients.

The Q&A period that yielded the above observations was very informative. Dr. Selesnick made clear throughout that there will always be numerous "on the other hands" when discussing treatment options for AN.



ANA/NJ Winter Meeting

“Share & Care”

**An informal gathering of members, family and friends
for sharing experiences and information about
acoustic neuroma ~**

February 4, 2007

2PM

Immaculate Conception Parish Center

Munn Street & N. Fullerton Ave

(Just off Bloomfield Ave)

Montclair, NJ

Directions

As maps for NE Jersey will show, Bloomfield Ave is a major east-west avenue connecting with the Garden State Parkway, Bloomfield, Montclair, Verona, W. Caldwell, Rts 46 and 80. N. Fullerton Ave crosses Bloomfield Ave in Montclair. You will see the towers of the large Immaculate Conception Church when you are at the intersection of Bloomfield Ave and N. Fullerton. There is a furniture store on one corner. The Parish Center on Munn Street is to the right of the Church. Parking is available.

What is the Real Incidence of Acoustic Neuroma?

Dr. M. Tos and colleagues at the Gentofte Hospital, University of Copenhagen, have been keeping track of the incidence of acoustic neuroma/vestibular schwannoma in Denmark (population ca. 5.1 million) for more than 25 years. In 1992, they reported that the incidence of these tumors had increased from 7.8/1 million of inhabitants per year for 1976-83 to 9.4/1 million inhabitants per year for 1983-90. The next report in 1997 described a further increase to 12.4/1 million for the period 1990-95. The increase was attributed mainly to more newly diagnosed intracanalicular and small tumors. On the other hand, they saw a decrease in newly diagnosed "giant" tumors. Another report (September 2000) by Dr. Tos and colleagues prepared at the Institute of Cancer Epidemiology in Copenhagen concluded that the overall incidence of AN had increased "... probably owing to the introduction of more precise diagnostic procedures, increased awareness among physicians and patients of the symptoms of VS [vestibular schwannoma], improved registration of benign tumors in Denmark, and the use of data from two sources [the Danish Cancer Registry, and a clinical database at the Gentofte University Hospital]." The most recent study (Feb 2004) by Dr. Tos and his group looks at the 6 years from January 1996 to December 2001 and reports that the incidence of AN increased during this period to 17.4/1 million inhabitants per year. For the 542 cases of AN diagnosed, 227 underwent surgery, 14 were irradiated, and 301 were assigned for observation (wait-and-watch). Looking back over the whole period of study, the report concluded: "An estimate of a realistic mean incidence of VS [acoustic neuroma] depends on the observation period. Our 25.5-year registration of an entire population showed a mean incidence of 11.5 VS/1 million inhabitants per year. However, the latest period registered represents an incidence of 17.4 VS/1 million inhabitants per year, which, combined with a probable further increase of diagnostic tumors in forthcoming years, suggests a realistic incidence of approximately 13 VS/ 1 million inhabitants per year."

Table 1

Incidence of AN/1 million inhabitants
per year in Denmark

1976-83	7.8
1983-90	9.4
1990-95	12.4
1996-2001	17.4
Overall Realistic Incidence	13.0

(Editor's note: For New Jersey, with a population of about 8.6 million, the incidence of acoustic neuroma has been estimated at 10 AN/ 1 million inhabitants per year, or about 80-90 new cases of AN each year.)

*References: M.Tos et al, "What is the Real Incidence of Vestibular Schwannoma?" *Arch. Otolaryngol.Head Neck Surg*, vol 130 (Feb 2004); "Incidence of Vestibular Schwannoma in Denmark," *Am J Otol*, vol 21 (Sept 2000); "Increase of Diagnosed Vestibular Schwannoma in Denmark," *Acta Otolaryngol Suppl*, vol 529 (1997); "Incidence of Acoustic Neuroma," *Ear Nose Throat J*, vol 71 (Sept 1992). Abstracts in PubMed.

Drug Information

To read about a drug your doctor may have prescribed (e.g., side effects, recommended dosage, etc) there is a new website, www.PDRhealth.com, based on the Physicians' Desk Reference. Besides "Drug Information," the website has substantial sections for "Disease Overviews," "Treatment Options," and "Clinical Trials."

Health News Website

A new website, www.healthnewsreview.org, will monitor and rate health news coverage in top newspapers, magazines and other media outlets. The free site was created by Professor Gary Schwitzer of the University of Minnesota. Professor Schwitzer directs a graduate program in health care journalism.

Early Detection of Disease

A new website by Harvard professionals (www.YourDiseaseRisk.com), encourages its visitors to take several specially prepared online quizzes to check on how likely they are to develop various types of cancer, diabetes, heart disease, stroke or osteoporosis. The site has tips for prevention. "Over half of all serious disease in the United States could be prevented with healthier lifestyles," the site claims. The importance of screening tests is emphasized.

A new book with the provocative title "*The End of Medicine*," (Collins, 2006) presents the case that early detection will be the hallmark of medicine for the 21st century. The author, Andy Kessler, a former Wall Street analyst, has turned his attention to the healthcare industry in search of technological breakthroughs that will, he feels certain, transform the practice of medicine. The book's subtitle, "*How Silicon Valley (and Naked Mice) Will Reboot Your Doctor*," reflects the direction of his thinking. Kessler gets excited about the potential of cheap, mass market scanning and testing. In the book, he talks with biologists, chemists and engineers about harnessing the computer for this purpose. His message for modern healthcare consumers is: "Take control of your own [medical] information. Get scanned. Ask your doctor what new tests are available. Bug your insurance company to get reimbursed for new tests and procedures. . . Avoid getting sick by focusing on early detection. . . Get over the hump of not wanting to know." The book is not a thorough academic review of progress in medicine; it's more a series of entertaining stories about what the author has heard and seen in doctors' offices, hospital wards, pharmaceutical labs and at medical conferences. It's an enjoyable read for anyone interested in speculating about new directions in health care. For an interview with Kessler, see The Medical Blog Network, www.healthvoices.com/blog.

Kessler's book focuses on early detection of the "big killers" -- heart disease, stroke, cancer. As for rare brain tumors like acoustic neuroma, which are not cancers but where early detection is also important, pre-symptomatic imaging rarely occurs. ANs get diagnosed mainly when someone shows up in the doctor's office complaining of hearing loss and/or tinnitus and/or imbalance. But by the time of these first symptoms the tumor can be so large as to limit treatment options and worsen treatment outcomes in terms of hearing preservation and facial function. "What we really need to get to is pre-symptomatic diagnosis."

This quote is from a paper entitled "Acoustic Neuroma Research" by Robert L. Martuza, MD (ANA NOTES, No. 80, December 2001). For possible early detection of AN, Dr Martuza presented the following very interesting recommendation: "Over the next number of years, I think you'll be seeing treatments for Alzheimer's disease and for multiple sclerosis. Therefore, although the government may not recommend screening 20 to 50-year-olds for acoustic neuromas because of the low incidence in the general population, as a group you may be able to get together with some other groups that deal with MS and Alzheimer's, and consider strategies for early

screening. The MRI scan, compared to having a colonoscopy, is a trivial venture and has little or no risks. If pre-symptomatic brain MRIs were possible, I think that would have a huge impact and would change the way acoustic neuromas are treated and would change the outcome for patients with acoustic neuromas. It would almost eliminate facial nerve palsy. In a majority of cases, it would leave people with hearing intact. . . Pre-symptomatic diagnosis! As a group, it is something you can work toward.”

Cochlear Implant Hybrids

The October 2006 issue of the newsletter briefly described the new cochlear hybrid that combines a shortened cochlear implant for high frequency sounds with a traditional hearing aid for low frequency sounds. Dr. Mark Ross, Professor Emeritus of Audiology at the University of Connecticut, has evaluated the hybrid and notes that preliminary testing has been encouraging. In particular, tests have shown that “hybrid implants not only improve speech perception ability compared to that obtained with just hearing aids, but that they also increase speech perception scores in [noisy “babble” situations] compared to what people using the traditional cochlear implant could achieve.” Secondly, comprehension and enjoyment of music for hybrid users was much better than for the traditional implant users. “The hybrid implant subjects (short electrode) obtained an 80% score on the [melody recognition test], or close to the 87% that the normally hearing people achieved. In contrast, the scores of the group with the traditional cochlear implant (long electrode) was only 27%. The higher scores obtained by the hybrid group was attributed to the fact that the fundamental frequency of nearly all musical instruments lies below 740 to 1,000 Hz.” At the end of the article, Professor Ross states: “I would not be surprised to learn that hybrid implant users would shortly be exceeding the number receiving traditional implants.” (The full article by Prof. Ross, entitled “Different Kinds of Implants: Auditory, Penetrating, and Hybrid,” Aug. 7, 2006, may be read at www.healthyhearing.com/library.)

Dr. David Gantz and colleagues at the University of Iowa, where the hybrid was pioneered, have reported in *Laryngoscope* (May 2005) and *Audiol. Neurootol.* (October 2006) on clinical trials for their shortened implant – the Iowa/Nucleus 10 mm electrode. Two small groups of subjects who received the implants were studied. The Iowa report concluded: “The surgical strategies have been successful in preservation of low-frequency hearing in 96% of individuals. Combined electrical and acoustical speech processing has enabled this group of volunteers to gain improved word understanding as compared with their preoperative hearing with bilateral hearing aids and a group of individuals receiving a standard cochlear implant with similar experience with their device. The improvement of speech in noise and melody recognition is attributed to the ability to distinguish fine pitch differences as the result of preserved residual low-frequency acoustic hearing. Preservation of low-frequency acoustic hearing is important for improving speech in noise and music appreciation for the hearing impaired, both of which are important in real-life situations.”

Anyone interested in learning more about the hybrid and implant candidacy should read the article by Myles Kessler, Au.D. “Cochlear Implant Hybrids: Who is a Candidate? You May be Surprised” (Mar 20, 2006), which can be found on the Internet at www.audiologyonline.com/articles. The article is important in particular for calling attention to problems associated with the implant. For example, “there is a risk of permanent irreversible damage to residual hearing fibers from the surgery and placement of the electrode itself. A larger long-term concern is associated with future changes in hearing in the implanted ear. Specifically, should the patient experience additional hearing loss, will they need additional surgery using a longer (standard) electrode?” Improved surgical techniques, insertion tools and electrode arrays are being worked on. Just recently we learned of the development by Dr. Kensall Wise and colleagues at the University of Michigan of an implant with sensors that signal for adjustments during the critical insertion process. (*Science News*, Jan 14, 2006)

ANA/NJ Spring Meeting

“Options for Better Hearing”

Speaker : Elizabeth (“Liz”) Cook
Chief Audiologist, Morris Audiology & Hearing Ctr.
Morristown, NJ

April 29, 2007
1 PM Conference Room 3
Morristown Memorial Hospital

Discussion

Social Time

Refreshments

Directions to Morristown Memorial Hospital, 100 Madison Ave, Morristown, NJ

From northeastern New Jersey

Take I-80 West to I-287 South to Exit 35, marked Madison Avenue. Turn left at traffic light onto Madison Avenue. Make left at next traffic light to Hospital entrance.

From northwestern New Jersey

Take I-80 East to I-287 South and then follow directions from northeastern New Jersey (above).

From central and southern New Jersey

Take I-287 North to Exit 35, marked South Street. Turn left at traffic light at end of ramp. Bear right onto access road toward Madison Avenue. Turn right onto Madison Avenue. Make left at next traffic light to Hospital entrance.

From Newark Area

Take I-78 West to Route 24 West to I-287 South and follow directions from northeastern New Jersey (above).

From eastern Pennsylvania

Take I-78 East to I-287 North to Exit 35, marked South Street, and follow directions from central and southern New Jersey (above).