



ANA/NJ Newsletter

Vol. IX, No. 3 (May 2005)

Meeting at Overlook Hospital April 3, 2005



Program chairperson Phyllis Schreiber introduced our speaker, **Dr. Richard M. Hodosh**, chief of neurosurgery at Overlook and Morristown Memorial Hospitals and long-time member of ANA/ NJ's Medical Advisory Board. During his informal question-and-answer presentation dealing with "Regrowth of Acoustic Neuroma," Dr. Hodosh focused mainly upon how the rapid development of radiosurgery/radiotherapy and MRI imaging has resulted in new approaches to the problem of tumor recurrence. Risky attempts at total removal of large tumors, for example, can now be avoided in the knowledge that troublesome "residuals" can be treated subsequently with precise Gamma Knife or CyberKnife radiation. With the increased availability of these instruments, regrowths no longer require a second invasive surgery in all cases. And monitoring "residuals" or any treated tumor for possible regrowth can be done effectively using periodic MRIs to determine more exactly when or if intervention is needed. Dr. Hodosh went on to speculate that, as more and more acoustic neuroma patients opt for either primary or follow-up radiation treatment, the number of cases treated surgically will continue to decline, as will the number of surgeons especially trained to do AN surgery. Dr. Hodosh, who is a very well-trained and dedicated surgeon, said he was happiest doing surgery, but that he understood and could be enthusiastic about the importance for the future of instruments like CyberKnife. Already, Overlook Hospital's recently acquired CyberKnife has been used for about ten acoustic neuromas. Asked at the end of his presentation about the cause of acoustic neuroma, Dr. Hodosh said that it was most likely a genetic marker being somehow triggered. He thought the marker would soon be identified.

Save the Date!

ANA/NJ meetings
are being planned for:

July 10, 2005

October 16, 2005

1-3p.m.

(See newsletters for details)

Brain Awareness Week

ANA/NJ participated in Brain Awareness Week (March 14-20, 2005), an annual event sponsored by the Dana Alliance for Brain Initiatives (www.dana.org). A committee headed by Jane Huck mailed letters to the editors of 25 newspapers in New Jersey describing the event and highlighting the special nature of acoustic neuroma, its symptoms and treatment options.

Tinnitus Conference

Wilma Ruskin and Dave Belonger attended the Mid-Atlantic Tinnitus Conference in Voorhees, NJ (March 19, 2005). There were presentations for special hearing aids and the various therapies available to reduce the effects of tinnitus. Another session examined drugs known to induce tinnitus, such as aspirin, Ibuprofen, Lasix, quinine. Of special interest was Dr. Richard Salvi's report on the continuing research at the University of Buffalo's Center for Hearing & Deafness, where PET scans (positron emission tomography) are being used for the identification of sites in the brain responsible for tinnitus.

Tinnitus Awareness Week

The American Tinnitus Association (ATA) will hold its second Tinnitus Awareness Week from May 21-28, 2005. Tinnitus, also known as "ringing in the ears" or "head noise," affects one in six Americans and is a problem for many acoustic neuroma patients. There are no cures, but many people find a treatment or management technique that brings relief. There are many excellent healthcare professionals who take an active interest in treating tinnitus patients. ATA has established a special financial assistance fund to help pay costs, up to \$750, associated with the treatment of tinnitus.

For more information about ATA, visit its website at www.ata.org, call 800-634-8978, or write to ATA, PO Box 5, Portland, OR 97207.

Directory Mailed

The 2005 ANA/NJ Directory of Members & Friends was mailed April 20. If you are an active member or subscriber and did not receive your copy, please call Jane Huck (908-725-0233) or email her at janehuck@msn.com.

Nancy Bonnet in the Spotlight~



Nancy wants to use her medical expertise to open doors for others to follow her through. Her knowledge of the medical insurance industry and terminology has allowed her to push the coverage envelope, getting full coverage for her **BAHA** surgery and instrument. The road to that place was a difficult one but Nancy has barely allowed it to slow her down although she acknowledges a change of priorities. Nancy grew up in Bloomfield, NJ, the youngest of five children. She earned her BSN, married John, her high school sweet-heart, and went on to earn her MFN in advanced practice nursing while beginning her own family. Nancy and John have three children, Patrick, age 11, Jack, 7, and Emma who is 4½. Nancy became a Cardiac Clinical Nurse Specialist and helped to found the Congestive Heart Failure Center at Mountainside Hospital. She was focused and goal-oriented, enjoying her work and her growing family.

When Nancy's mother's ovarian cancer returned, Nancy and John opened their home, renovations and all, to her parents who came to live with them for what turned out to be her mother's last month of life. Nancy took a leave of absence to be more available to her parents, and to her young children including infant Emma. On Mother's Day, several months after her mother's death, Nancy felt her mother's presence telling her it was now time for her to take care of herself. She was out to lunch with John, her sister and brother-in-law when she experienced facial numbness. The next day during a hospital (JCAHO) review, she experienced numbness in one-half of her tongue. In retrospect, she realizes she had been experiencing some one-sided hearing loss and balance deficits but hadn't paid attention to them. A Romberg test, touching fingers to the nose, caused her to fall over and an MRI with contrast revealed a 3.7 cm acoustic neuroma.

Nancy did research and interviewed several doctors before proceeding to surgery. She concedes that even if radiosurgery had been an option, she wanted to get the tumor out of her head. She chose to have surgery at the House Ear Clinic in California. She was impressed with their surgical strategy, their responsiveness and the very large number of surgeries they were doing. They were doing as many surgeries in a week as local experts were doing in a month. Ironically, House Ear was "in-network" for her insurance while closer facilities were out-of-network. If she has any criticism of House Ear and of doctors in general, it is their inattention/insensitivity to the challenges that surgical complications present to the AN patient. Her translabrynthine surgery left her with facial weakness, single-sided deafness, spinal fluid leak (resolved with tight bandaging) and balance problems that were very hard to accept. After all, she was only 35 years old and at the top of her game. Now her children were upset by her absence and the changes in her appearance, and she had trouble accepting her reflection in the mirror. As if all of this was not enough, her husband had a melanoma around the same time. She had also lost a dear friend and colleague to a tragic and unexpected death. It was a lot to cope with.

On the other hand, Nancy was deeply moved by the support of family and friends.

John's cousin moved in to watch the children while she and John went to California. Her sister also came to be with her after the operation. A dear friend provided Nancy with a 1st class plane ticket to make the trip more comfortable. Nancy's neighbors banded together to deliver full meals daily, and transportation for the children for three months! Her friends and colleagues at Mountainside Hospital raised money and paid for in-home help during her recovery! Family and church members were also great supports.

In June 2003 Nancy attended the national ANA conference in California. There she tried the BAHA test band and was determined to get the implant. She also heard Jackie Diels talk about her work with facial reanimation. She traveled to the University of Wisconsin in November to spend several days learning how to massage and exercise her face with feedback using a mirror. She hopes to be able to return at a later date but has not been successful with her insurance to date.

Nancy then visited Dr. Kwartler in NJ to pursue having the BAHA implanted. He was skeptical that insurance would cover it and quoted a large out of pocket cost. Nancy was determined that it should be covered. She contacted the "rep" at Entific, the BAHA manufacturer, to get helpful information. Then, with the help of Jeanette in Dr. Kwartler's office, and the Human Resources Department at her husband's employer who insured her, she was able to provide sufficient documentation/justification to have the whole procedure and the instrument covered.

Nancy had the titanium implant inserted in July of 2003 and the hearing aid was hooked up that October! After having had brain surgery, this procedure was a breeze! Within a few hours after the procedure, she was home making dinner for her family. It was done under IV conscious sedation and she experienced no pain. The area became numb for several months and she had a bandage on her head for a week. A nickel-sized area was shaved but is not visible. She has occasionally had a little soreness in the area but on those occasions she applies a little Neosporin and the discomfort is gone by the end of the day. She can even sleep on that side now! Nancy does make the effort to keep the area very clean, primarily using a toothbrush to clean the area to avoid infection.

Nancy has been very pleased with her results. Her hearing is much improved with the device and she does well even in difficult hearing situations. She concedes that nothing is as good as "real" hearing but she found it fairly easy to adjust to and a vast improvement over the deafness. In the beginning, when she wore it all day at work, she would find it fatiguing. She described it as almost like having a person talking in her head. On those days, she would take the hearing device off when she got home.

Nancy and John have not allowed their struggles to hold them back. If anything, they have shifted priorities allowing them to start their own business, a dream of John's. Using his experience as a photographer, engineer, his experience with e-commerce and his MBA, he has opened the Finer Photo in Roseland. They develop film, have a portrait studio, and provide a full complement of digital imaging services. Nancy continues to work in nursing and nursing education. She looks for reasons for everything that has happened and tries to make something positive for each difficulty. Part of that purpose is education, and part is pursuing insurance coverage, which might make it easier for patients who follow her. Although at moments the pain of her losses affects her, for the most part she has a full and busy life and is determined to make the most of it.

Interview by Kristin Ingersoll

(For any questions, Nancy can be reached at nancy@thebonnets.com)

Scanning: CT or MRI?

In an article entitled “Radiation Risk from CT Scans: A Call for Patient-Focused Imaging” (*Medscape Radiology*, vol. 6 [1] 2005), Dr. Richard C. Semelka expresses his serious concerns about the rapid growth of x-ray-based CT scanning in the USA, and recommends the expanded use as far and as soon as possible of safer diagnostic imaging tools, notably, MRI and ultrasound.

Dr. Semelka, who is Professor of Radiology at the University of North Carolina, is worried in particular about the lifetime cancer risks involved with diagnostic CT for young children as well as for those patients who receive serial CT examinations during treatment of long-standing disorders or chronic pain. He calls attention to a recent study in the radiology literature showing that patients are practically never informed about the effects of radiation exposure; and, more surprising, that the majority of radiologists performing CT scans are themselves unaware of the amount of radiation delivered or the increased lifetime cancer risk involved. “Physicians in general,” he adds, “have not been overly concerned about the radiation related to CT investigation.” About 60 million CT scans are performed each year in the USA. But the excitement over the wonderful imaging capability of CT has not been tempered by sufficient understanding of the potential harmful effects of excessive radiation exposure.

Dr. Semelka observes how CT radiation exposure can be limited to a degree through using lower settings for pediatric patients, small adults and for lung screening studies. But he recommends – and this brings us to the main point of his article – that “an even better approach is to avoid radiation altogether by performing MRI. . . . Up to now, MRI has often been thought of as an alternative to CT investigation, either in patients who have contraindications to CT (allergy to contrast agents or poor renal function) or in whom CT findings are considered inconclusive. The prudent approach for the future may be a change in the paradigm of imaging investigation to less harmful techniques, with the preferential use of ultrasound (US) or MRI when accuracy of these techniques is approximately equivalent to CT, and CT reserved as a problem-solving modality and for those indications in which CT is clearly superior.” For example, CT is clearly superior for the evaluation of primary lung disease, whereas, on the other hand, MRI has greater accuracy over CT in liver investigation. Patients should be made aware that, for many indications, there are alternatives to CT which may in fact be safer and more accurate.

“In my opinion,” Dr. Semelka writes, “one of the greatest potential harms that exist in patient care today is the injudicious use of CT by many physicians, as they unwittingly subject patients to the untoward effects of ionizing radiation. This is especially unfortunate because often MRI may be employed instead, with greater diagnostic accuracy and greater patient comfort. In diagnostic situations in which the diagnostic information of CT is superior to MRI at the present moment . . . CT should be treated as the temporary imaging method of choice, until technical improvements in MRI result in an image quality that approaches the consistent accurate information of CT, and at that time [MRI] should replace CT as the primary tool for these imaging indications.”

Dr Semelka anticipates one likely reaction to his recommendation: “A common sentiment expressed to me by radiologists is that they would do more MRI examinations for various indications, such as liver investigation, but that they do not have enough MRI scanners to serve all of their patients. My response to them is simple: Invest in more MRI systems for the benefit of patients.” •

Radiation Treatment Outcome

Drs. John Flickinger, Douglas Kondziolka and L. Dade Lunsford of the University of Pittsburgh Center for Image-Guided Neurosurgery have reported that the lower-dose radiation prescriptions of 12 to 13 Gy currently in widespread use for Gamma Knife radiosurgery treatment of acoustic neuroma have been found to be effective for tumor control and have reduced complications. At Pittsburgh during 1991-2001, for 313 AN patients treated by Gamma Knife at 12-13 Gy, the tumor control rate was 100%, facial nerve preservation was 100% and hearing preservation was 70-73%.

During the 1980s, patients typically received doses of 16-20 Gy, but these dosages began to be reduced to 12-13 Gy in the early 1990s. The authors observe that optimum and minimal doses for tumor control have yet to be defined for either radiosurgery or fractionated radiotherapy. They expect that tumor control rates would begin to fall off at 5-9 Gy.

Comparing data for outcomes reported in several recently published series for both radiosurgery (SRS) and fractionated radiotherapy (FSR), the study concludes that, especially since the introduction of the lower-dose prescriptions, FSR does not provide any useful advantage over SRS for preservation of hearing or facial nerve.

(See J.Flickinger et al, "Fractionation of Radiation Treatment in Acoustics: Rationale and Evidence in Comparison to Radiosurgery," in *Neurochirurgie*, vol.50, June 2004).

The latest issue of *Brain Talk* (vol.9, No.2, 2004), published by the International RadioSurgery Association, IRSA, also reviews current outcomes reported in the literature (2001-2003) for the different types of radiation treatment available for acoustic neuroma. A valuable summary table included in this special report (p.8) shows that the best overall results have been obtained with Gamma Knife. For the preservation of useful hearing, the outcomes reported are: Gamma Knife and Linac radiosurgery, 70-71%; Linac fractionated radiotherapy, 47-61%; one-session Proton Beam, 33%; and fractionated Proton Beam, 31%. For the incidence of facial weakness, the outcomes reported are: Gamma Knife radiosurgery, 1-4%; Linac radiosurgery, 8-12%; Linac fractionated radiotherapy, 2-12%; one-session Proton Beam, 9%; and fractionated Proton Beam, 0%.

Frequent reports such as these are very important in view of the constant improvement in radiation techniques used for treatment of acoustic neuroma. IRSA urges patients to seek out the most up-to-date information on outcomes in the peer-reviewed literature.

Update on Regrowing Hair Cells

In 2003, Yehoash Raphael and colleagues at the University of Michigan Medical School reported remarkable success in regrowing hair cells in adult guinea pigs by injecting *Math1* genes into the inner ear of test animals. Now, two years later, using auditory brain stem response, the Michigan team has been able to show that hearing actually returns in animals treated with the gene. Further experiments with this technique are underway.

(See ANA/NJ Newsletter, Sept.2003; *Science News*, vol.167, Feb. 19, 2005).

Meanwhile, at the Massachusetts General Hospital in Boston, researchers using mice have isolated a gene (*Rb1*) that acts to stop the growth of hair cells. They will seek to block the action of the gene to see if they can induce hair cell regeneration. (See *Science*, Jan., 2005) And perhaps the most challenging research is taking place at the House Ear Institute in Los Angeles, where scientists are attempting to trace the path of development of hair cells backward to the embryo. (See *House Calls Magazine*, vol.2, Spring 2002).

ANA/NJ Meeting
July 10, 2005
1 p.m.
Montgomery Center for the Arts, The 1860 House
Skillman, NJ

An Informal Patient Panel Discussion

Our Panelists will be:

Pam Betterton (Lawrenceville), Gamma Knife
Nancy Bonnet (N.Caldwell), BAHA
Kathy Dylewski (Sparta), Cochlear Implant
Kristin Ingersoll (Rockaway), Middle Fossa Surgery
Joel Krause (Rockaway), Family member
Irv Serkin (Toms River), Wait & Watch

Discussion Social Time Families Welcome Refreshments
(Meet at the picturesque 1860 House, home of the Montgomery Center for the Arts)

Directions to The 1860 House, Montgomery Center for the Arts

From Somerville: Go south on Rt. 206 approximately 15 miles passing Belle Mead, Harlington and the traffic light at Orchard Hill Road. Make a left onto Montgomery Road. The 1860 House (photo above) is on the left about one-half mile as the road bends around to the right. (If you come to Rt. 518 before making the left turn, you have gone a bit too far -- go back to Montgomery Rd).

From Princeton: Go north on Rt. 206 approx. 5 miles and go past Rt. 518. About one-half mile past Rt. 518 and the shopping centers, turn right on Montgomery Road. The 1860 House is on the left about one-half mile.

From north NJ using Turnpike: Go south to Exit 9. Follow signs to Rt. 1 south. Take Rt. 1 south approx. 5 miles and make a right on Henderson. Go one mile and take a left on Rt. 27 south. Go 5 miles and take a right on Rt. 518 west. Go 4 miles, past Rocky Hill, and take a right on Montgomery Road. The 1860 House is at the bend in the road approx. 1 mile on the right. (If you go further west on Rt. 518 and come to Rt 206, turn right on Rt. 206 and follow the instructions above for Princeton.)