ANA/NJ Newsletter
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Winter Meeting in Montclair

On February 4, 2007, board member Jon Bonesteel hosted a well attended "Share and Care" meeting at the parish center of Immaculate Conception Church on Munn Street in Montclair, NJ. The lively discussion centered on treatment options for acoustic neuroma. Members of the group shared their personal experiences. Wilma Ruskin and other ANA/NJ board members were present. Great refreshments were provided.

Spring Meeting in Morristown

On April 29, 2007, the Spring meeting was held at Morristown Memorial Hospital in Morristown, NJ. Our speaker was Elizabeth ("Liz') Cook, chief audiologist at Total Hearing Care on Madison Avenue in Morristown. Liz is well-known to ANA/NJ and is an excellent speaker. Her topic for this meeting was "Options for Better Hearing." She quickly established that we are currently living at a time of rapid design change and steadily improved technology for hearing systems. In the past three years especially, she noted, digital aids have advanced remarkably. Feedback problems are being remedied. We now have digital, wireless Cros systems. Multi-channel aids are helping with tinnitus problems. Surgical solutions (e.g., BAHA) are also now available, although still expensive. And there are now so-called "open ear" systems that do away with the bulky, too tight ear molds of analog days. Liz passed around samples of "open ear" acoustics manufactured by the Oticon and United companies. Oticon's "Delta" system, which is the recent winner of *Best of Innovations 2007 Design and Engineering Award* (American Consumer Electronics Association),was remarkable for its unique, triangular amplifier; thin, transparent sound wire; and tiny in the canal speaker. It was extremely light in weight. It comes with state-of-the-art noise reduction and directional systems and can be had in a variety of colors. Liz demonstrated a magnetic battery remover to deal with the tiny battery in the device. (For full facts and features, go to www.Oticonusa.com.) There were many good questions for Liz to answer. This was an excellent meeting for being brought up-to-date about what's new in the hearing systems business.

ANA National Symposium & Patient Survey

Several of our members attended ANA's 18th National Symposium held in Philadelphia (July 13-15, 2007) sponsored by the Department of Neurosurgery (Dr. David Andrews, Chair) Jefferson Medical College. ANA's founder, Ginny Fickel Ehr, was present to help celebrate the 25th Anniversary of ANA. Audio **CDs** of the various sessions & workshops are available to order at www.anausa.org (click on Cambridge Transcriptions) or phone Wilma Ruskin for special assistance.

It was announced at the symposium that a **2007 Patient Survey** would be made available soon online. The survey is now ready to take -- simply go to www.anausa.org and follow the easy instructions.

Hunterdon Memory Center

The Central New Jersey Memory Center has been established at Hunterdon Medical Center in Flemington, NJ. The center, which is part of the hospital's Center for Healthy Aging, tests cognitive functioning and provides counseling and therapy for people with memory problems. The number to call is 908-788-6373.

Monmouth Brain Tumor Center

Nancy Conn-Levin (Monmouth & Ocean County Brain Tumor Support Group) has called our attention to the recent establishment of the David S. Zocchi Brain Tumor Center at Monmouth Medical Center in Long Branch, NJ. The medical director of the center is neurologist and neuro-oncologist Dr. Sumul L. Raval. The center has announced that it will soon be equipped with Gamma Knife technology. For more inform-ation, go to www.sbhes.com/hospitals/Monmouth, or call 1-877-577-9800.

In Memory
Julian Barnett

*We were deeply saddened by the death of **Julian Barnett**, one of the founder-members of ANA/NJ. Julian's wife, Sue Barnett, the AN patient in the family since 1980, is also one of our founder-members. We extend condolences to Sue and family.*

Wilma Ruskin in the Spotlight~

Somehow, through all of the adversity, Wilma has found the silver lining in her pain and suffering. Having had a 2 cm acoustic neuroma removed suboccipitally in 1992 followed by Gamma Knife radio- surgery in 2003, she says she has no regrets. "I've been given the gift of compassion for others because of my own experiences, and the ability to give hope and strength because of it." Her gift is to take those experiences and use them when new patients call her seeking support. This has given her life great meaning that enriches her as it helps us. Wilma feels that the hard times she has experienced have given her the ability to appreciate the good times. The balance of both continue to weave through her life in amazing and complicated ways and the acoustic tumors have played an integral part in it. (See "Stories" at www.ananj.org to read more about Wilma's microsurgery experience with her tumor.)

Wilma was divorced in 1981 but re-connected with her ex-husband around the time of her microsurgery. They began to see more and more of each other starting around 1993 and moved in together in 1997. She says it was really a new relationship because they were not the same people they had been when they were first married and had their family. She had learned that she could be independent and self-reliant. This gave her a greater self-confidence. He, perhaps as a consequence, no longer felt the need to take care of her yet in his own way he became more helpful in a way that she could appreciate.

When a regrowth was identified, Wilma joined the growing ranks of "wait & watch" patients knowing that she was not going to have microsurgery again. Her recovery had been complicated and difficult and it was just not a consideration for her. She found that she was calmer than she might have been at an earlier time. She felt as if "all of the bad stuff had already happened to her" and she chose not to worry about it. After some years, her tumor doubled in one year to 2 cm so Dr. Kay recommended that she do something. She talked to Dick Barker (editor of this newsletter) and did her research, and decided to go to the University of Pittsburgh for Gamma Knife Radiosurgery. She took her MRI to them, which was reviewed, and a determination was made that she would be an appropriate candidate. Dr. Douglas Kondziolka was the neurosurgeon there. Wilma has no recollection of the procedure beyond seeing the instruments. She and Norm arrived a day in advance of the procedure, and met with the whole team. The procedure was done the next morning. She stayed over one night, and went home the next day. Wilma experienced extreme fatigue after the procedure but otherwise had no issues. She has now experienced all 3 treatment options and values the fact that she can share those experiences with other patients when they call her.

Two follow-up MRI's have been done. The first one was 6 months post-radiosurgery and a second MRI done at one year post showed the tumor was necrotic with some shrinkage. She will have a 3rd status update in October of this year. She has had other health issues, as has Norm as well, but they have chosen to affirm and celebrate their lives together and the love they have for one another.

On May 8th, 2007, Wilma and Norm sent the following announcement:

"WILMA RUSKIN, NORMAN RUSKIN"
are delighted to announce that they have once again married - ***each other****!*

The ceremony was held on Saturday, May 5, 2007, and was attended by the couple's four children, their spouses, six of their seven grandchildren, a few close friends and relatives - none of whom were at the first ceremony in July 1958!
The bride will keep her name.....

Wilma's sense of humor is obviously still intact, as is her desire to help other patients in their times of need. She continues to serve as President of the Acoustic Neuroma Association of New Jersey, and to be the voice on the other end of the phone when any of us call the chapter for information and support. The NJ Chapter has resumed its affiliation with the National ANA which, in a seeming symmetry, is almost another remarriage after a period of divorce from the larger organization.

Wilma's life, though never easy, has come into a certain balance which she accepts with grace and humility. She takes from every experience she has to give more to us, her fellow AN travelers.

PubMed! "The True Liberator of Medical Knowledge"

If you are newly diagnosed with acoustic neuroma and thinking of using the Internet to check on treatment options and outcomes, here's an excellent recommendation by Dr. Bernadine Healy, the past director of the National Institutes of Health (NIH) Bethesda, Maryland: "The true liberator of medical knowledge is the National Library of Medicine [on the campus of NIH]. The NLM is no stuffy ivory tower for doctors. Under almost 20 years of physician Donald Lindberg's leadership, the NLM has zealously pursued the goal of making medical information free, open and easily tapped. The crown jewel of this quiet revolution is the modestly named PubMed (www.pubmed.gov). Virtually all published medical articles from the thousands of professionally recognized and peer- reviewed journals are archived on that site in summary form. I encourage you to learn how to access this public treasure. PubMed comes with a powerful search engine that will quickly identify by topic virtually all research reports from accredited peer-reviewed journals [16 million citations in journals back to the 1950s]." (See "Power to the People," *USNews&WorldReport*, Sept 8, 2003).

As an example of how PubMed has helped the ANA/NJ newsletter -- for our notice about "CyberKnife at Stanford" in the April 2006 issue, we began by putting the PubMed opening page up on our computer (www.pubmed.gov), and then typed the terms *CyberKnife* and *radiosurgery* into the search box provided. Next, before clicking on Go, we selected AbstractPlus in the Display box, 20 (items) in the Show box, and chose Date in the Sort by box. A click on Go then gave us a display of 20 journal citations (out of a total of 116 available), arranged by date of publication, including Dr. Steven Chang's "Staged Stereotactic Irradiation for Acoustic Neuroma" *Neurosurgery*, vol.56 (June 2005). Clicking on this citation gave us a one-page abstract of the journal article. We selected to report on Dr. Chang's work for the newsletter. His abstract was well-written and summarized in sufficient detail for our purposes the results of his study of 270 patients treated by CyberKnife at Stanford University during 1999-2005. The abstract page also gave titles of sample studies for comparing treatment outcomes for microsurgery and Gamma Knife radiosurgery, and there was a place to click for all related studies. Dr. Chang's email address was provided, as well as the mailing address for the Department of Neurosurgery at the Stanford University School of Medicine.

This is all quite amazing! Anyone who has ever tried a catalogue search in a Medical School Library will appreciate just how much time (and frustration) was saved using PubMed!

It should be said that some PubMed abstracts are disappointingly brief, and that they all lack the valuable tables, charts and discussion sections of the original articles. Reading the full text of any scientific journal article is always to be preferred. PubMed does provide links to free full-text copies, if they are available, or links for ordering the full article from a reprint company (usually at too high a price, we think). There's a FAQ section with instructions about special orders. Of course, you might simply take the citations you've found in PubMed to a nearby Medical School Library (e.g., Newark) and read the journal articles there. Easier would be to write or email the first author of the article at his/her institution to request a reprint of the article you wish to see. Identify yourself as an acoustic neuroma patient who would greatly appreciate receiving such and such a reprint. In our experience, most authors are pleased to receive reprint requests.

Acoustic Neuroma & Memory Problems

Memory is the diary that we all carry about with us. (Oscar Wilde)

The true art of memory is the art of attention. (Samuel Johnson)

Oscar Wilde's definition of memory is catchy, but not especially appropriate for present purposes. That is, acoustic neuroma patients who have experienced postoperative memory problems seldom complain of loss of memories of the remote past such that a diary stores. Uncle Louie's riotous 65th birthday party can still be recollected vividly. The complaints focus rather on increased frequency of annoying lapses in short-term memory, like forgetting keys, or names, or where the car was parked, or forgetting whether or not the oven was turned off. And there are other really attentional problems, such as difficulty sustaining concentration, troubles remembering words, keeping up with the flow of group conversations, multitasking. As will be seen, these are the types of complaints that make our second quotation from Dr. Johnson much more pertinent.

In her excellent article, "A Purely Personal Report on Memory and Acoustic Neuroma" (ANA "Voyages," December 1993), Barbara Kristaponis described her serious difficulties with fatigue, anxiety, depression and memory following surgery for a 5 cm. tumor "very close to the brainstem." She wrote: "I used to work in documentary television. Sometimes I worked as a camera-person in studios with large crews. Always central to my work was being mentally on top of a number of things at the same time. . . . [But] I can't do this kind of thing now. I cannot focus on a camera lens and keep my camera steady at the same time. I also confuse red and green traffic lights while trying to cross the city streets, shampoo my hair twice because I forget the first time, and forget to send checks in with the bills. I forget what I am talking about to a friend if the waiter interrupts us; and I often can't remember the words of my work – microphone, reflector, grip stand – not once in awhile, but a lot. I don't know how I am going to earn my living again. This is not like me. I used to be sharp."

Exactly why acoustic neuroma surgery can result in memory problems was not known in 1993, nor are specific causes agreed upon today. A PubMed search for scientific articles on memory problems and acoustic neuroma was as fruitless then as now. Research has been lacking. The common assumption has been that the parts of the brain concerned with memory are not the parts of the brain affected by acoustic neuroma. Apparently, the fact that surgery for acoustic neuroma was resulting in cognitive changes only began to receive some attention after the problem was reported by 7% of responders to the national Acoustic Neuroma Association's 1983 patient survey. This was reinforced by ANA's next survey in 1998 when 25% reported memory problems and 20% said they were having difficulty with concentration. ANA's bi-annual symposia now regularly include sessions dealing with cognitive changes.

At the 1997 Symposium in Dallas, TX, for example, Dr. Bruce Mickey, a neurosurgeon at Southwestern Medical School, proposed that one part of the brain that may be affected by acoustic neuroma surgery is the temporal lobe. The temporal lobe, which is responsible for storing short-term memory, is located close to where an AN grows. Dr.Mickey observed that translab or retro- sigmoid surgery would put no stress on the temporal lobe's memory circuitry. However, the retraction of the temporal lobe required when using the middle fossa approach could injure this part of the brain and cause memory problems.

Dr. Mickey considered two other anatomic possibilities: brain stem compression and vestibular nerve damage. Both, he thought, were not directly or seriously involved with memory problems.

He took issue with the hypothesis of Dr. Kenneth Erickson that the brain stem and the vestibular system are important structures for memory (See "Cognitive Aspects of Vestibular Disorders," 1998 VEDA Conference, Portland, OR). He did observe, however, that vestibular disturbances (imbalance, vertigo, dizziness) can influence memory by contributing to stress, fatigue and depression – all factors that detract importantly from our ability to pay attention and learn new information. In this connection, a recent Harvard University special health report on memory has stated: "The memories that endure will be those that were encoded most completely in the first place – the information that you paid the closest attention to when you learned it. When you have trouble remembering a piece of information, it's often because you weren't paying close attention when you first encountered it." Short-term memory that the mind stores only temporarily, such as a new name or number, is especially fragile and easily lost unless reinforced. (See Aaron Nelson, ed., "Improving Memory," Harvard Health Publications, 2006).

Acoustic neuroma patients, of course, run the risk of encountering a variety of "attention-busters," such as hearing loss, imbalance, tinnitus, headache, fatigue, sleep disorder, stress, eye problems, change in facial appearance. As Dr. Mickey emphasized, dealing with side effects of AN surgery such as these can for some patients lead to "reactive depression," which is itself well-documented as a cause of difficulties with attention, concentration and memory.

~ To be continued, next issue of the Newsletter ~

Chapter Meeting

"Vestibular Rehabilitation for Acoustic Neuroma Patients"

Jennifer Paventi Legendre
Senior Physical Therapist, JFK Rehabilitation Institute, Edison, NJ

October 7, 2007
JFK Medical Center Auditorium
1 PM
Refreshments Discussion Social Time

Directions to JFK Medical Center, Edison, NJ

From New York or Newark. Take the NJ Turnpike south to Exit 11. Pick up the Garden State Parkway North to Exit 131, making a right turn off the exit to Route 27. At the fourth light (James St), make a right turn . JFK Medical Center and parking Lot A will be a short distance on the left.

From Garden State Parkway South. Take the Parkway to Exit 131 and continue as above, except note that you will enter Route 27 past the first traffic light.

From Philadelphia & South. Take the NJ Turnpike north to Exit 10 and pick up Route 1 North. At the Menlo Park Mall, exit on the right, going around the jughandle onto **Parsonage Road**. Continue straight past the mall and go through the underpass to the traffic light at Route 27. Go through the light onto James Street. JFK Medical Center will be a short distance on the left.

(Convenient, ample parking is by the main entrance.)