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ANA/NJ Newsletter
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Acoustic Neuroma Association of New Jersey
291 Nassau Street
Princeton, NJ 08540

ANA/NJ

Wilma Ruskin, President
291 Nassau Street
Princeton, NJ 08540
609 683-4650
ananjinc@aol.com

Dick Barker, Newsletter Editor
115 Barbertown-Pt Breeze Rd
Frenchtown, NJ 08825
908 996-3155
rbarker465@aol.com

Jane Huck, ANA/NJ Directory
65 E Young Street
Somerville, NJ 08876
908 725-0233
janehuck@msn.com

**Meeting at Overlook Hospital
October 10, 2004**



Phyllis Schreiber introduced our speaker, **Dr. Michael Schulder** (photo above), Co-Director of the Center of Stereotactic Radiosurgery, New Jersey Medical School. Dr. Schulder began his presentation on “Radiosurgery and Radiotherapy” by stating his opinion as a neurosurgeon that surgery remains the ‘gold standard’ for treatment of acoustic neuroma. That is, assuming a successful, complete tumor removal with no serious complications or chance of regrowth, the surgery patient is “home free.” The tumor is gone and normal life is resumed. But the surgery option, he went on to say, can involve risks: for large tumors especially, the incidence of facial nerve damage is still high and hearing preservation rates remain unsatisfactory. A growing number of acoustic neuroma patients are selecting other treatment options. Dr. Schulder pointed out a recent survey of 130 patients at the Mayo Clinic showing that, while 40% opted for surgery, 36% chose radiosurgery and 23% decided to wait-and watch. Outcomes for single-session radiosurgery and fractionated (multiple-session) radiotherapy have improved greatly during the past decade as standard radiation dosages were decreased, MRI used for target planning and new instrumentation introduced. Gamma Knife data from the center at the University of Pittsburgh was presented to illustrate impressive rates of tumor control and hearing & facial nerve preservation. Dr. Schulder called attention as well to the relatively new CyberKnife developed by Dr. John Adler at Stanford University. CyberKnife is a miniature but powerful linear accelerator (Linac) attached to a computer controlled robotic arm. No head frame is required to restrict movement; instead, patients are fitted with a custom molded face mask. Overlook Hospital has been using the machine since June 2004. Dr. Schulder predicted that outcomes for CyberKnife should be pretty much the same as for Gamma Knife. Patients often ask about the risk of a radiation induced malignant tumor; Dr. Schulder said it is very small, with only a handful of cases reported over the past 30 years.

Dr. Schulder’s presentation was taped by Dave Belonger and will be made available for audio replay on our new website, www.ananj.org.

The BAHA Seminar, Dec 2004

About 70 people attended the BAHA (Bone Anchored Hearing Appliance) informational seminar held at Overlook Hospital auditorium on December 12, 2004. The main presentation by Dr. Jed Kwartler (Ear Specialty Group, Springfield) was first-rate; Rose Pattavina described her personal experience with the BAHA system; and there was a very lively Q&A period. Ed Murray representing Entific Medical Systems (www.entific.com) was on hand to answer technical questions and also to help attendees use a “test band” to see how BAHA might improve their hearing. For SSD, Single Sided Deafness, the BAHA system – titanium implant, external abutment, detachable sound processor – is an alternative to the CROS (contra lateral routing of signal) hearing aid worn by many acoustic neuroma patients. The system was cleared for SSD by the FDA in 2002. In use in Europe since 1977 for various types of hearing loss, about 18,000 people worldwide now have BAHA implants. A directional microphone for noisy environments was added to the system in 2002 and is currently being upgraded. About 70% of users have reported a better quality of life with the BAHA. It’s always advisable to wear the “test band” for a few days to check out the system. Dr. Kwartler did an excellent job using slides to illustrate the 20-30 minute outpatient surgical procedure needed for the titanium implant in the skull bone behind the ear. Rose Pattavina kindly allowed attendees to examine her external abutment and how the sound processor attached and could be concealed under her hair. Rose regretted that her tinnitus remained, and she still has difficulty in very crowded, noisy places (as others have reported), but overall she was very satisfied with her new bone conduction hearing. Nothing is as good as a normal ear, but technology keeps moving us along in the right direction.

(Note: Videotapes or DVDs of the seminar are available at \$10 each. Please contact Wilma, or call Dave Belonger at 609-654-8141.

Dave Belonger in the Spotlight~



Growing up in Wisconsin, the oldest of 8 children and the child of a struggling artist and furniture upholsterer, Dave knew he wanted to find a career that would allow him to provide a different type of life for himself and his family. Although he could appreciate his father’s many talents from painting and carving to furniture design, Dave’s interests and talents seemed to lie in the sciences. He always had a chemistry set, the enjoyment of which was evidenced by holes left in his dresser top from experiments. An uncle advised him that it would be more financially rewarding to be a Chemical Engineer than a chemist so by High School, before he understood what that meant, he settled on his career.

Working his way through college, he met his future wife, Kathie, who attended a neighboring nursing school. They laugh now remembering how, to meet her, he complimented a salad she made for a social event admitting later on that he didn't really care for salads. They were married a year and a half after he graduated from college. A summer job between his Junior and Senior years at Rohm & Haas Co. led to a 32-year career there going from research to production management and operations. Dave's career took him, Kathie and their two children, Jeff and Heather, from Philadelphia to Bristol, PA, to Houston, TX, Louisville, KY, and back to Philly and Bristol. Although they prefer the small town environment of Louisville, their network of friends and family is well established now in New Jersey after having spent 20 years in a 10-mile radius before retiring in 1997. Their four grandchildren also live in Medford, and are a great joy to them. Three of them were adopted from Kazakhstan with the latest addition arriving this November 2004!

It's hard for Dave to understand how his acoustic neuroma was missed by all the doctors for 30 years. His hearing loss and tinnitus dated back to college in 1964. The doctors there and later at his annual employment physical, told him it was caused by nerve damage most likely from loud noise, possibly from hunting in his youth. Fifteen years later, as his symptoms progressed, he went to another hearing specialist who confirmed the earlier diagnosis and said there was really no effective treatment. In the early 1990's he began having headaches at the base of his head but believed stress was the cause. It wasn't until 1997 when they changed family doctors that his new doctor, after reviewing the 5-page history form, considered his symptoms together and sent him for a CT scan followed by an MRI.

Dave was shocked when he was told the results. He felt strong and healthy but was being told that he had a benign brain tumor that was beginning to compress his brain stem. This meant that radiosurgery was not an option. He knew that his neurosurgeon, had an excellent reputation, so without doing much research, he proceeded to surgery. He would later realize that although the doctor might be an excellent neurosurgeon, he did not have a lot of experience removing acoustic tumors. Dave was devastated when he awoke from his translabyrinthine surgery with facial paralysis. Although the facial nerve was not severed, the 2x3 cm tumor had been very sticky and the facial nerve was badly damaged and a small portion of the tumor remained near the brain stem. In addition to the issues of appearance, speech clarity and eating, he had excruciating eye pain and no ointment had been prescribed. The doctor wanted him to proceed without delay to Gamma Knife radiosurgery but Dave held out hoping facial nerve function would return. Five months later, without any return of nerve function, he proceeded to have Gamma Knife radiosurgery.

Over the next four years, Dave took every step he could to regain facial function and symmetry. He had a gold weight inserted in his eyelid, a canthoplasty and tarsorrhaphy to protect his eye. He found a doctor in Virginia to do a cross-facial nerve graft and partial hypoglossal (the latter returned facial symmetry at rest and was the most helpful of the procedures done). It took a year for the nerves from the "good side" to connect to the paralyzed side and he was supposed to follow up with a muscle graft to round the flaccid cheek. Ultimately, he had had enough and decided not to proceed with more surgery but he traveled to Wisconsin for neuromuscular retraining.

Dave had retired a month before his first surgery intending to travel with his wife and friends and then begin his own consulting business. Things did not turn out as he had envisioned. On their Ireland trip, one month after his AN surgery, he was miserable with eye pain and dizziness. The new business had to be put on hold for a year for follow-up medical procedures and recovery. His appearance, concentration and ability to articulate were all factors holding him back.

Dave says that the only positive he can think of for the delay in his diagnosis is that he can't imagine how he would have handled the consequences of his surgery when he was younger. Even so, it has been extremely difficult to cope with and he has found ANA/NJ to be very helpful both for getting and giving support and information. The support and encouragement he received from his wife and family was especially critical to his recovery. He continues to be self-conscious about his appearance, though he doesn't dwell on it, and he continues to have headaches and difficulties with his hearing loss. After two cataract surgeries, his sight is much better and he is working on his own schedule with a limited number of clients, and enjoying the grandchildren. A naturally private person, Dave agreed to share his story as part of that support he finds so important to ANA/NJ.

In addition to Dave's other activities, he and Kathie are members of the Board of Directors for ANA/NJ. They have hosted satellite meetings in South Jersey, and Dave has been active in developing the terrific new website at www.ananj.org.

Interview by Kristin Ingersoll

Major Survey of AN Patients

ANA/NJ has been asked by IRSA, the International RadioSurgery Association, to help sponsor and design a major survey of acoustic neuroma patients. This will be the first broad survey to give special attention to investigating the incidence of any short-term complications and/or long-term "Quality of Life" problems associated with today's different types of radiation treatment. Radiation treatment centers at the Universities of Pittsburgh and Virginia will participate. Some ANA/NJ members have already assisted with proposed questions for the survey. If you have any "must" questions for the survey, please contact Dick Barker by email or phone.

Introducing New Ideas in Medicine

In his book entitled *Working in a Very Small Place: The Making of a Neurosurgeon* (1989), Mark Shelton tells the fascinating story of how Dr. Peter Jannetta, Chairman of the University of Pittsburgh Department of Neurosurgery (1971-96), introduced and perfected the surgical technique of microvascular decompression (MVD) for the treatment of trigeminal neuralgia and hemi-facial spasm. The 'very small place' in the book's title refers to the cerebellopontine angle on the underside of the brain – the very small and dangerously delicate surgical arena where Jannetta found offending blood vessels pressing on cranial nerves and carefully moved them away with the insertion of a tiny Teflon pad. The important idea Jannetta added to his profession may be simply

stated: “Neurovascular compression can cause cranial-nerve disorders, and microvascular decompression can cure them.” For the many patients relieved of the excruciating facial pain of trigeminal neuralgia, Jannetta’s procedure meant the wonderful return to a normal life.

Getting the profession to recognize MVD as an acceptable procedure was not easy. In fact, the author likens the process to other struggles for change in science described by Thomas Kuhn in his study on *The Structure of Scientific Revolution*. Kuhn argued that scientific communities are notoriously conservative with set ideas and common understandings that are not easily modified or put aside. Change is resisted, or comes slowly, if at all. Jannetta himself, reflecting on the resistance he encountered, eventually concluded: “It takes twenty years for anything new to really catch on, not because it takes that long to convince the establishment, but because it takes that long for there to be a changeover to people who have grown up with the new idea as being accepted.”

Actually, an earlier effort to establish the procedure had failed. The neurosurgeon Walter Dandy (d.1946) at Johns Hopkins University described the approach to the trigeminal nerve within the cerebellopontine angle as early as 1925, and reported on hundreds of his own successful operations. But the procedure never caught on. Why? Based on his own experience, Jannetta explains: “Dandy wasn’t able to do what he had to do outside the operating room. He was advocating a difficult procedure that was unsafe unless the neurosurgeon had been well trained in the technique. He didn’t train a large number of surgeons to do the procedure, which is necessary if something is going to be kept alive. One surgeon, no matter how much he operates, has very little effect. But if he trains a group of surgeons who go forth and multiply and train others, then the ripple effect is tremendous.”

Jannetta did all these things. He trained 49 residents. He wrote journal articles and presented papers at conferences. He reported tirelessly on his procedure. He politicked. And very important as well, as author Mark Shelton observes, Jannetta in the 1980s had the advantage of new technologies – the operating microscope, video monitors, ‘shadowless’ lighting, evoked potentials of cranial nerves, advances in anesthesia. In other words, “working in a very small place” was still dangerous, but not as much as in Walter Dandy’s time.

Even safer for trigeminal neuralgia patients in more recent years has been noninvasive stereotactic radiosurgery, the Gamma Knife, introduced at Pittsburgh by Dr. L.Dade Lunsford. Lunsford joined Jannetta’s department in 1975 and became its chairman in 1997. But Lunsford’s is another fascinating chapter in the history of the introduction of new ideas in medicine.

Acoustic Neuroma and Fatigue

(The first 3 parts of this article, which dealt with the incidence, nature and causes of AN-related long-term fatigue, appeared in the June 2004 issue of the newsletter.)

IV.

How can I cope with long-term fatigue?

Let's begin with observations sent in by our members. Thus, at random: "Take things slow and rest can't be stressed enough." "I'm learning everyday how to manage my fatigue. . . Less stress, more relaxation, [be] aware of my environment, more down time. . ." "I do all my 'thinking' work in the morning, saving my physical chores, exercise etc., for the afternoon." "I have reduced my intake of stress [at home and at work]." "I find the way to combat fatigue is to push the envelope. . . similar to building muscles, the more you keep pushing yourself the more growth you'll experience." "I try to take the good points. . . I can leave parties early now or arrive late, say no to functions, take more vacations to relax." "Balance has become less an issue for me as time goes on, and exercise definitely helps."

We notice that these are mostly coping skills; no one wrote in with a sure-fire "cure." Time is mentioned as curative; after all, whatever is "out of whack" may just remedy itself over time. But for the interim at least, our members are calling attention mainly to helpful lifestyle adjustments. In the literature on fatigue, making post-treatment lifestyle changes like this is often referred to as moving on to a "new normal" life.

Here are some suggestions gleaned from the literature on fatigue:

- ◆ Eat a well-balanced diet and consider using nutritional supplements.
- ◆ Manage fatigue by scheduling activities for times when you feel most energetic.
- ◆ Establish good sleep habits. Try for 6-8 hours each day. Go to bed and get up at about the same time every day. In the four hours before retiring, do not exercise or nap, and avoid caffeine and alcohol. An after-noon nap is OK, but for no longer than 30-45 minutes.
- ◆ Try to arrange a low-stress environment.
- ◆ Avoid taking sleeping pills as much as possible. They can disrupt your normal sleep cycle.
- ◆ Try using a hearing aid. Fatigue can be a consequence of the energy used compensating for a hearing deficiency.
- ◆ Keep as active and involved as possible and try to avoid negative thinking, which can lead to depression. Depression can result in fatigue; antidepressants can interfere with sleep.
- ◆ Regular light exercise, such as walking, has been shown to decrease fatigue. Exercise promotes a healthy body, helps to reduce stress, and may also help you to sleep better at night.

As life goes on, fatigue-causing conditions not related to AN may intrude to complicate things. Several members, for example, have experienced hypothyroidism, and there have been a couple of unfortunate encounters with fibromyalgia. Fatigue can also be caused by diabetes, iron deficiency anemia, shortness of breath, sleep apnea, stress, prescription drugs, or even a special condition being defined as chronic fatigue syndrome (CFS). In one of the strangest recent cases, a woman reported that the fatigue her doctor diagnosed as CFS was actually caused by a defective auto exhaust pipe that filled her car with carbon monoxide for a half-hour every morning and evening. Her auto mechanic discovered the defect, fixed the pipe and cured her fatigue.

Meeting

“Regrowth of Acoustic Neuroma”

Dr. Richard M. Hodosh

Chief of Neurosurgery –Overlook & Morristown Hospitals
Director of the Neuroscience Institute, Atlantic Health System

**April 3 1 PM Conference Rm 4
Overlook Hospital, Summit, NJ**

Discussion Social Time Refreshments

Directions to Overlook Hospital

Route 24 West: Take exit marked Milburn-Springfield-Summit. Bear right to Broad St and follow blue Hospital signs up the hill.

Route 24 East: Take the Summit Ave exit. Follow Summit Ave thro downtown, over RR bridge and thro light at Broad St. Make next left at Walnut St and follow blue Hospital signs.

Garden State Pkwy, South: Take Exit 142 for Rt. 78 West to Rt. 24. Then follow directions for Rt. 24 West, above.

Garden State Pkwy, North: Take Exit 142 (stay in extreme right lane at the toll plaza!). Take the exit for Rt. 78 East immediately after the toll plaza. Proceed about one mile on Rt. 78 East to the sign for a U-turn to Rt. 78 West. Take Rt. 78 West to Rt. 24 (be in right lane). Follow directions above for Rt. 24 West.

Route 78 East: Take Rt. 78 to exit marked Summit-Glenside Ave. Make a left at the light onto Glenside. Follow Glenside about 2 miles to blue Hospital sign. Go left on Baltusrol Rd, and make a sharp left up the hill on Morris Ave at the next blue sign. Follow signs for a right turn to Hospital.

Route 78 West: Take Exit 49 to Rt. 24 West. Follow directions above for Rt. 24 West.

NJ Turnpike, North or South: Take exit marked Newark Airport to Rt. 78 West. Follow 9 miles to Rt. 24 West (stay in right lane). Follow directions for Rt. 24 West, above.

(At the Hospital, use Parking Garage and bring ticket to be validated. Conference rooms are down the hallway to the right of the Coffee Shop.)

Membership/Donation Form

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Renewal

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Contribution Categories

Member Status

Suggested Donation

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- Medical Practitioner

All donations are tax deductible as the law allows.

<p>Please make all checks payable to: ANA/NJ Inc 65 E.Young Street Somerville, NJ 08876</p>	<p>With all donations, members will receive a quarterly newsletter, directory, notices of local meetings, pamphlets and other information.</p>	<p>For membership in the national association, write to: Acoustic Neuroma Association 600 Peachtree Pkwy, Suite 108 Cumming, GA 30041</p>
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I would like to contact other members in my area.

Please remove my name from the mailing list.