



**ANA/NJ Newsletter
April, 2008**

On October 7, 2007, the Fall meeting of ANA/NJ was held at JFK Medical Center in Edison, NJ. Our speaker was Jennifer Paventi Legendre, Senior Physical Therapist at the JFK Johnson Rehabilitation Institute. Jennifer received her degree in Physical Therapy from the SUNY Health Science Center in Brooklyn, NY (1997) and specializes in the treatment of vestibular and orthopedic disorders. The topic she addressed for this meeting was “Vestibular Rehabilitation for Acoustic Neuroma Patients.” She began by observing that post-op complaints by AN patients include: fatigue; instability when turning quickly; greater difficulty walking in the dark; difficulties when walking on uneven surfaces such as grass; problems with changes in light intensity. She noted that three types of inputs are affecting balance in these cases: visual (orientation of eyes and head in relation to surrounding objects); somatosensory (information on the orientation of body parts to one another and support surfaces); and vestibular (measures gravitational, linear, and angular acceleration of the head). The vestibular plays more of a minor role when visual and somatosensory are available or in cases when an individual is essentially sedentary. The vestibular deals with precise control of head and eye movement and is critical when other inputs are unavailable or misleading. The vestibular ocular reflex (VOR) generates eye movements that enable clear vision while the head is in motion. The vestibular spinal reflex (VSR) generates compensatory body movements to maintain head and postural stability. The goal of therapy is to determine by testing just exactly what is out of whack and do something about it to decrease any disequilibrium, improve balance when walking, and improve the ability to see clearly during head movements. Jennifer discussed the types of treatment available (adaptation, substitution, habituation) and related exercise programs. She distributed a small booklet entitled “Guidelines for Creating Individualized Home Exercise Programs,” illustrating types of specific exercises. Treatments can take 4-6 weeks or up to 6 months in some cases. Patients with less initial disability and those seen early have better recovery.

There were many questions throughout Jennifer’s presentation. This was an excellent meeting for learning how to cope with balance problems.

Support for ANA/NJ

ANA/NJ’s executive board, in grateful appreciation, wishes to recognize those who made special financial contributions during 2007:

Associates – Mildred Capuro, Ronald Gelfuso, Dorothy Greene, Andy & Jeane Gregg, James Gregoire, Letty LaForgia, Nicole Mirsky, Michael Illuzzi, Ann Radley, Dirk Richter, Claire Rosenbaum, Barbara Schwartz, Norm Wellen, Emily Wein, Helen Vaccaro, Margie Wasserman

Supporters – Joe Dombrowski, Bob & Phyllis Dougherty, Geoffrey Green, Joan Grossman, Martin Kain, Lorraine Puccio, Wilma Ruskin, Jim Shields, Frances Statter

Benefactors – Myrna Cummings, John Rivers (in honor of Wilma Ruskin), Dr. Samuel Selesnick

Matching Gifts – Israel Heilweil (Mobil Retiree Matching Gift Program)

Memorial Gifts (In Memory of Julian Barnett):

Dick Barker, Sue Barnett, Jane & Charles Huck, Wilma Ruskin.

(In Memory of Shirley Kwartler):

Dr. Jed Kwartler

Dr. Schulder Heads New Institute

Dr. Michael Schulder has been named first director and vice-chairman of neurosurgery of the Harvey Cushing Brain Tumor Institute, North Shore LIJ Health System. Dr. Schulder's responsibilities will include development of the Stereotactic Radiosurgery Center (Novalis system) at North Shore University Hospital.

Congratulations to Dr. Schulder!

Joe Dombrowski in the Spotlight

No one was more surprised than Joe that he was walking in for brain surgery of his own free will, feeling perfectly normal yet subjecting himself to all of the risks entailed. Self-described as squeamish, liable to pass out at the sight of blood, it was a sign of the great confidence he had in the surgeon he had finally selected after interviewing several others

Joe grew up in Raritan, NJ, the youngest of six children. His father died when he was only six months old and his mother somehow managed to raise her children while working at night. The oldest child at the time was only 12 so she had six little ones to raise on her own. Joe's not really sure how his mother did it except to say that she is an incredibly strong woman and she had the support of her extended Czech family as well. He feels grateful that she passed that strength on to



him. Joe fondly remembers being able to go anywhere on his bike or by foot as a kid in Raritan. He was athletic and enjoyed playing baseball and basketball. Not knowing exactly what he wanted to do for a living, he followed his older brother's advice and pursued an education in electrical engineering after High School. He attended Union County College and then transferred to NJIT where he changed his major to computer science.

After graduation, Joe began his career at IBM, and enjoyed the young bachelor life for a few years. He has worked for a variety of companies since, frequently having jobs interpreting technical Information Technology (IT) jargon into non-technical language. He always grew the job as far as he could and then moved on for one reason or another. He is currently the manager of Store Systems, administering all IT for Charming Shoppes including all technology for 2500 stores.

Joe's wife Lara is an x-ray technician at Robert Wood Johnson and he met her through his best friend Matt who was dating, and later married, Lara's friend. Joe and Lara's first date did not start auspiciously as Joe was late and Lara was so quiet. Somehow they began seeing each other and two years later they were married. They now have two beautiful daughters, Casey who is 8, and Madilyn who is 5.

On the Sunday before Halloween in 2006, Joe woke up and noticed that the hearing in his right ear was muffled. He immediately went to Urgent Care. This was followed by a visit to his ENT, Dr. Sabin, who did a hearing test which confirmed one-sided hearing loss. Dr. Sabin, gave him prescriptions for prednisone and for an MRI with and without contrast. He also advised Joe to see Drs. Kwartler and Eden at the Summit Medical Group, who he knew did steroid injection therapy. Dr. Eden explained to Joe that there were several possible causes for his one-sided hearing loss including a possible tumor. Steroid Injection Therapy was not a pleasant experience, and although his hearing loss resolved, it was probably a result of the prednisone he took reducing the tumor size just enough to eliminate the pressure on a blood vessel. Joe didn't feel it was necessary to have the MRI, but Dr. Eden advised that he should have the MRI anyway. He said: "I can tell you that (pointing) this is an empty closet, but unless you open it and look inside, you won't know for sure." As Joe will tell you now, his closet was unfortunately not empty.

Joe had his MRI at Robert Wood Johnson and the results showed he had a benign (1.1 cm) tumor. He went online that night and read about it and became extremely scared. He could only read a little bit at a time because he couldn't handle what he was reading. He saw all the possible complications that could occur and over the next few weeks found himself alternately laughing and crying and running the gamut of extreme emotions. With Lara's help, he visited several surgeons, but until he went to NYU and met Dr. Roland, he did not feel comfortable or confident with any. After meeting Dr. Roland, both Joe and Lara knew they had found the right surgeon. Joe never considered radiosurgery because he and his wife were concerned about the long-term effects considering his young age. He knew he could never be a "wait-and-watch" because he did not have the personality that could deal with that. Joe's uneventful 3-1/2 hour retrosigmoid surgery took place January 10, 2007, two months after his diagnosis. The doctors said his tumor "popped out like a grape."

Joe feels he had a very good outcome from his surgery although he had extreme fatigue at first and did lose some hearing (now at about 40% but the tone is good). When Joe first ventured out into the world again after his surgery he found it difficult to handle the amount of sensory stimulation, even at the library. He returned to work fairly quickly but still had problems with his balance, especially when it was dark. His balance took 9-10 months to resolve. Now he feels, a year after the fact that he is fully back to normal. Lara believes he still tires faster, but that is up for debate. He says he is back to jogging and golfing, and his one-year MRI was clear! He is more than satisfied with his choices and is very open and eager to talk to others who are starting their AN journey. He wants to help others who are afraid, as he was, and feels this is something new and meaningful for him. He hopes to contribute his energy to his fellow AN travelers as a member of the Board of ANA/NJ.

Interview by Kristin Ingersoll

Acoustic Neuroma & Memory Problems

Part 2

In the past, we believed that in the brain, one neuron equaled one memory, and that each section of the brain performed its particular operation in isolation. . . Today. . . [modern]instruments such as PET scanners show us that the brain is more like an active ecosystem than a static, preprogrammed computer. . . Indeed, bits and pieces of a single memory are stored in different net-works of neurons all around the brain. We bring the pieces together when it is time to recall that memory.

(From John J. Ratey, MD, *A User's Guide to the Brain*, Pantheon Books, 2001)

The first part of this article began to look into possible causes of memory problems being reported by AN patients. Like other investigators before us, we found no basic research on the subject. A PubMed computer search drew a blank. The only efforts to address the issue were found in the newsletters of the American and Canadian acoustic neuroma associations. For ANA's *NOTES* (No. 48, Dec 1995), Robert Frazier, PhD, a neuropsychologist, speculated that the *locus ceruleus*, an area of the brain stem that plays a role in attention, learning and memory, might be disturbed by AN surgery and thus account for memory difficulties. For Canada's *The Connection* (Vol. 7, Dec, 1994), Deirdre Dawson, M.Sc., a research clinician who has studied memory problems related to brain injuries, wrote about how memory usually works and how treatment for acoustic neuroma might interfere with the memory process. "To date," she wrote, "there is little evidence to support the idea that ANs interfere with the attentional and memory anatomical structures." Ms.Dawson mentioned how Dr. Frazier and Dr. Kenneth Erickson have "theorized" about the brain stem and vestibular system, respectively, but her focus was on side

effects of acoustic neuroma surgery – loss of hearing, balance problems, pain, depression and fatigue – as more likely causes of attentional and memory deficits for AN patients. On the other hand, as noted in Part 1, neurosurgeon Dr. Bruce Mickey speaking at the 1997 ANA symposium in Denver, proposed an anatomic cause by noting that injury to the temporal lobe during middle fossa surgery for AN could result in memory problems. We asked Dr. Jed Kwartler of our Medical Advisory Board to comment about this and he responded: “I have not heard of this specifically, long-term, in my patients. . . It is well-documented and commented on in the anesthesia literature and neurosurgical literature that both medications and manipulation can cause these types of complaints. It certainly can be a short-term postop effect (that “foggy” feeling that lingers). If retraction is long enough or a bit too much pressure I suppose there could be some longer lasting effects.”

The anesthesia literature mentioned by Dr. Kwartler has been reporting for some time that memory loss and problems with concentration are frequently experienced by patients who have undergone a surgical procedure. A British report in *Anesthesiology* (vol.96, June 2002), for example, states that: “Postoperative cognitive dysfunction after noncardiac surgery is strongly associated with increasing age in elderly patients; middle-aged patients (aged 40-60 yr) may be expected to have a lower incidence, although subjective complaints are frequent.” In this study group, three months after surgery “29% of patients had subjective symptoms of POCD (postoperative cognitive dysfunction), and this finding was associated with depression.” The report concluded: “Patients may be helped by recognition that the problem is genuine and re-assured that it is likely to be transient.” Interestingly, this same “genuine but transient” appraisal is how neuropsychologist Dr. Edwin Barrett concluded his presentation on AN and memory at the 2001 ANA symposium held in Cincinnati. Further, in the absence of any research to the contrary, Dr. Barrett stated his opinion that it’s not the acoustic neuroma that’s the problem; rather, the problem is the surgery itself – the tests, the anesthesia, the whole traumatic process, including possible energy-attention-sapping side effects such as fatigue, hearing loss, imbalance and depression. Probably this is the place to add that there have been warnings that the cumulative effect of multiple exposures to anesthesia may accelerate brain aging and related memory loss.

In Part 1, attention was called to ANA’s 1998 survey (*The Acoustic Neuroma Experience, 1998. Member Survey*) which placed “Memory Problems” fairly high on the basic list of postop complaints made by acoustic neuroma surgery patients (Table 4). The complaint was also voiced among the much smaller number of radiation patients responding to the survey. It’s important to note that none of the responders to this survey (a total of 1,940 patient-members) reported memory problems among “Initial Symptoms Prior to Diagnosis” (Table 2). In other words, memory problems if any were all seen as post-treatment. The survey (Table 5) did not define exactly what patients meant by “Memory Problems,” or distinguish the types of problems patients said were “permanent” or how long they had lasted.

For the most part, the memory problems communicated by ANA/NJ members for our Directory, or that we read of in ANA’s online Discussion Forum, are problems of short-term/working memory, such as forgetting names, faces, directions. This is not, of course, an exclusively AN problem, although treatment for AN for many people does appear to at least temporarily exacerbate the common art of forgetting things. AN patients anxious over postop problems with this type of memory ability might wish to look at “Rate Your Current Memory,” Chapter 2 of Dr. Gary Small’s *The Memory Bible* (Hyperion, 2002). Dr. Small is the Director of UCLA’s Center of Aging. His Chapter 2 includes a special self-assessment questionnaire for testing memory ability mainly of the short-term type. Other chapters describe ways to move on from there to improve memory ability through stress reduction, mental aerobics, diet, lifestyle changes, and care with medications.

Most short-term/working memories are relatively unimportant and are stored only temporarily and then purged by the brain. The important ones, on the other hand – e.g., the names of relatives, how to drive a car or run a household, the multiplication tables, the words of the Star-Spangled Banner – are stored permanently to become what we call long-term memories. It's when we ask about how and where these memories are stored, and how an acoustic neuroma and/or its treatment might interfere to affect the process, that we find how things are much more complicated than one might expect.

The quote from Dr. John Ratey's excellent recent study of the brain points up the problem; and a good example given in Harvard's health report, *Improving Memory* (2006) spells it out: "Each memory resides in a network of neuronal activation, dispersed across multiple brain regions. . . . The words of the Star-Spangled Banner are stored in the left temporal lobe, which processes language, but the melody would be stored in the left parietal lobe, which processes auditory patterns. And. . . if you associate [the song] with the image of the American flag, that memory might be stored in your occipital lobe, which processes visual information. Your memories are thus intricately broken down and cross-referenced Calling up memories is like doing an Internet search, with one or two words activating many hyperlinks."

PET scanning (Positron Emission Tomography) has made it possible for researchers to arrive at this important new understanding of how the brain works. Using PET, the brain's memory areas can be seen in action during particular testing activities. The Cleveland Clinic's health page explains: "The test involves injecting a very small dose of a radioactive chemical, called a radiotracer, into a vein of your arm. The tracer travels through the body and is absorbed by the organs and tissues being studied. [The] machine detects and records the energy given off by the tracer substance and, with the aid of a computer, this energy is converted into three-dimensional pictures. A PET scan can measure such vital functions as blood flow, oxygen use, and glucose metabolism, which helps doctors identify abnormal from normal functioning organs and tissues."

Dr. Small's book, *The Memory Bible*, has useful information about PET (See his Appendix 2 for "Brain Scans" and "Medical Screening"). For more detail, there's Joel Davis, *Mapping the Mind* (1997), Chap.3, "Mapping Machines," and Chap.8 "Memory and Learning."

There's no doubt that PET scanning would help to answer questions AN patients have about their memory problems. But at \$1200 or more per session, plus costs of related diagnostic tests, it doesn't seem likely that many AN patients – especially those with mild memory complaints – will decide to utilize this brain imaging technology. Dr. Small writes: "Anyone with a new concern about increased forgetfulness or a sudden change in memory ability should consult a physician and, if indicated, get a PET scan." However, we wonder, has anyone in ANA/NJ having memory problems actually had one of these scans? If so, we'd appreciate greatly hearing from you for this newsletter.

See Next page for Information on the next Chapter Meeting

Next Chapter Meeting

“Brain Tumors and Fatigue”

Nancy Conn-Levin, M.A.

Nancy Conn-Levin (a 12-year brain tumor survivor) is a health educator, specialist in stress management and coping techniques, and co-facilitator of the Monmouth & Ocean County Brain Tumor Support Group. She is author of *Brain Tumors and Fatigue*, a patient education guide sponsored by the Brain Science Foundation.

April 13, 2008

**Princeton Medical Center, Conference Room A
1 PM**

Refreshments

Discussion

Social Time

~All patients, family members & friends invited~

Directions to Princeton Medical Center, Princeton, NJ

From Route 1: Take Washington Rd (Rt 571) to Nassau Street in Princeton. Turn left onto Nassau Street to Witherspoon Street, and turn right. The Medical Center is about $\frac{3}{4}$ of a mile on the right. For the parking garage, turn right on Henry Street just past the Medical Center building.

From northern NJ, Rt 287/Somerville: Take Rt 206 from Somerville to Princeton. Turn left onto Nassau Street and go to Witherspoon St. Turn left. Follow instructions above.

From northern NJ using the Turnpike: Take the NJ Turnpike south to Exit 8. Take Rt 571 into Princeton and Nassau Street. Follow instructions above for Rt 1.

From Pennsylvania: Take I-95 north across the Delaware R. to the Princeton/Route 206 Exit. Take Rt 206 thro Lawrenceville to Nassau St in Princeton. Go to Witherspoon St and turn left. The Medical Center is on the right. For the parking garage, turn right on Henry St just past the Medical Center building.

Conference Room A is down the hall on the left just past the Information Desk

Please Save the Date – October 25, 2008

A special mini-conference is planned for our meeting on Saturday, October 25, 2008, 11:30-4:30/5, Berkeley Heights, NJ. The theme will be *“Acoustic Neuroma: Treatment Options and Quality of Life Issues”* Lunch to be provided. Stay tuned for details and registration instructions.

