ANA/NJ Newsletter

Vol.XI, No.4 September 2009

Chapter Meeting April 26, 2009
Berkeley Heights, NJ

About 31 people attended the Baha (Bone Anchored Hearing Appliance) informational meeting held at the Summit Medical Group complex in Berkeley Heights. Dr. Jed Kwartler, who is a member of our Medical Advisory Board, did the main presentation. Dave Burke representing Cochlear Americas (www.cochlear.com), was on hand to answer technical questions and assist people who decided to try the "test band" to learn how the Baha might improve their hearing ability. We were fortunate also that acoustic neuroma patient Catherine Garrison was present to answer questions about her personal experience with the Baha system.

As Dr. Kwartler explained, the Baha is a three-part system that includes a titanium bone implant (MRI compatible), a small external abutment and a sound processor. It requires minor surgery which is usually carried out under local anesthetic and takes about 30 minutes. The surgery is for placing the small titanium fixture in the skull bone behind the deaf ear. This implant bonds with the bone (in about six to eight weeks) in a process called osseointegration. The external abutment for holding the sound processor can for adults be attached to the implanted fixture during the surgery or in a second operation. The sound processor, in a variety of colors to match the patient's hair color, can be connected or disconnected at will by the user. When connected, the processor will transmit bone-conducted vibrational sound to the cochlea of the good ear. There is no ear mold or other device in or attached to either ear.

Dr. Kwartler, who has done about 30 implants, commented that the failure rate for the osseointegration process is around 5% for adults. He speculated that any prior radiation treatment in the implant area, as for example for acoustic neuroma, might influence the process negatively. He noted that those who do the implant surgery, himself included, are switching over from a skin flap to a simple linear incision procedure; this has made care of the wound site easier and lessened the chance of infection. In any case, he did not think that infection was a big risk. He cautioned that care needs to be taken with the abutment during showering, and hair coloring should be avoided during the first 8 weeks following the implant. He thought, too, that it would be wise to detach the sound processor while sailing (and of course showering).

Neither Tinnitus nor sound localization capability should be expected to improve because of the Baha, Dr. Kwartler advised. Catherine Garrison raised her hand to agree, and observed that, for her, one great advantage of the Baha was that she at least no longer needed to turn her head to hear people speaking near her bad ear.

What is the cost of the Baha? About $3000-3500, the cost of a high-end hearing aid. Baha is covered by Medicare. Private health plans vary in their coverage. (The Cochlear Americas website, we note, offers to help with insurance issues.)

Dr. Kwartler reviewed evaluations of the Baha, indicating that overall the system has received high marks. It is a definite benefit for persons having single-sided deafness and for those who cannot wear a conventional aid. It should not be confused with cochlear implants which are only for persons with significant hearing loss in both ears.

Dr. Kwartler's excellent presentation was taped by Dave Belonger. For a DVD copy, visit the website (www.ananj.org) or phone 609-654-8141.

Addendum

Recently available is another type of bone-conduction hearing aid, the TransEar, made by Ear Technology Company. TransEar looks like a conventional behind-the-ear aid, but it uses an oscillator on the bony portion of the ear canal in the deaf ear for conducting sound to the cochlea of the good ear. In effect, via components fit on and in the deaf ear, there is boneconduction hearing without the surgery needed by Baha. (See Ravi Samy & Julie Honaker, "Hearing Loss Rehabilitation for Acoustic Neuroma Patients," ANA ***Notes*,** Issue 102, June 2007).

Tumors Getting Smaller

ANA's 2008 Patient Survey shows we are spotting many more ANs before they become overlarge and difficult to treat. For the 1,934 respondents to the survey, 38% reported tumors 1.5cm or less at the time of diagnosis, compared to 23% for the ANA's 1998 survey and 17% for the 1983 survey. And yet, 155 respondents, 8%, reported tumors larger than 4.0cm at diagnosis. One can only wonder why these large tumors went undiscovered.

Our ANA/NJ Registry for NJ patients shows a similar decrease in tumor size at time of diagnosis. For the 39 tumors reported to us with size information for 2002-2008, 36% were 1.5cm or less. Only 5% (2) were over 4.0cm.

The "Dizzy Doctor" Website

For patients having dizziness and balance disorders, it may prove worthwhile to take a look at the website of Dr.Timothy Hain (known locally as the "Dizzy Doctor"), Professor of Neurology at Northwestern University Medical School in Chicago, www.dizziness-and-balance.com. The site has a valuable section for acoustic neuroma.

Notices

• Many thanks to Tim and Karen Reid for hosting a successful satellite meeting of ANA/NJ, February 22, 2009, at the Community Medical Center, Toms River, NJ. Seventeen people including board members attended. For any follow-up, Tim & Karen can be reached at 732-341-6002, or email tjrxxx@yahoo.com.

• The results of the national Acoustic Neuroma Association's "Patient Survey 2007-2008" can now be viewed at the website www.anausa.org. For a paper copy, please contact the ANA office at 770-205-8211, or for email, E-mail info@anausa.org.

● The sections of our website (www.ananj.org) for "Treatment Options" and for "Postop Conditions" have been revised and updated. Take a look, and please let us know if you have any suggestions for improving either section.

● The *Journal of BioPhotonics* (Feb 2009) reports that Dr. Claus-Peter Richter and colleagues at Northwestern University's department of otolaryngology have been developing a new form of cochlear implant, one that would use pulses of mid-infrared light instead of electricity for stimulating auditory nerve cells. The advantage, according to Dr.Richter, would be a clearer signal than is possible with existing technology.

• The website of the American Brain Tumor Association now provides information about forms of "therapeutic recreation" (art, dance, gardening, humor, music, etc) for helping individual reduce stress, depression, and improve motor and cognitive functioning. Go to www.abta.org and click on the heading Care and Support. Visit also the website of the American Therapeutic Recreation Association, www.atratr.org.

Proton-beam Update

For many years, proton-beam radiation therapy in the USA was available at only a couple of hospital-based centers – Loma Linda University Medical Center in southern California and Massachusetts General Hospital in Boston. Compared to the relatively small cost for an X-ray machine, the high expense of constructing a cyclotron and its associated massive gantries and beam transport systems for protons discouraged any rapid spread of the technology. But recently, as described by health-writers David Whelan and Robert Langreth in their article "The $150 Million Zapper," *Forbes* (March 16, 2009), a 'proton-beam construction boom' seems to be underway. The M.D. Anderson Cancer Center in Houston, Texas, completed its $125 million proton-beam facility in 2006, and there are now proton centers at the University of Florida and Indiana University. Other centers are in the works by private investors for Boca Raton, FL, Oklahoma City, Detroit and Chicago. And closer to home, the University of Pennsylvania expects to open a $144 million proton center this fall. According to *Forbes*, "Penn's center was built with a $15 million donation from the Roberts family of the Comcast cable fortune, plus money from Penn's affiliated hospitals and the government." Moreover, as a special advertising section in *US News & World Report* (April 2009) advises, the Cancer Hospital at Robert Wood Johnson University Hospital in New Brunswick, NJ, "plans to have one of the first single-vault (one-room) proton beam systems in the US – a more compact, less costly version of the conventional proton beam machine." The proton 'boom,' as the *Forbes* writers speculate, is "either a godsend to patients with intractable tumors or a stunning example of runaway health costs, or both."

The *Forbes* article reports that some 20,000 patients (all with tumors) have been treated with protons to date in the US. Prostate cancer patients especially have opted for the proton beam, but also patients with hard-to-treat spine, lung and brain tumors. The proton beam has the advantage in treating sensitive areas of a low entrance dose in front of the tumor, a high dose to the tumor volume, and no exit dose beyond the tumor. Treatment can be given as single-session radiosurgery or as multiple-fraction radiotherapy.

The most recent evaluation of proton beam treatment for acoustic neuroma comes from the Department of Radiation Oncology at Massachusetts General Hospital (*Neurosurgery*, vol. 53, September 2003). During 1992-2000, 88 patients were treated with proton beam radio-surgery. The median diameter of the tumors was 16 mm (range, 2.5 – 35 mm) and the dosage range was 10-18 Gy. The median follow-up period was 38.7 months (range, 12 – 102.6 months). The tumor control rate was 95%. One patient required additional radiosurgery; one craniotomy was performed; three shuntings for hydrocephalus; and one patient required a partial resection. Facial and trigeminal nerve preservation was rated excellent. On the other hand, of the 21 patients with functional hearing before treatment, only seven (33.3%) retained serviceable hearing ability. This low hearing preservation rate compares to 60 – 70% or even higher rates currently being reported for Gamma Knife and the Linac (X-ray) systems. It should be noted as well that fractionated proton beam treatments reported in 2002 by the Loma Linda center showed a 31% preservation rate, 4 of 13 patients (*Neurosurgery*, vol. 50, February 2002). Proton centers have begun to work with lower radiation doses.

The increased availability of proton radiotherapy is important for treating intractable tumors in very sensitive areas. *Forbes* reports that the M.D. Anderson center has begun a trial to compare protons to X-rays in 200 lung cancer patients. Meanwhile, for acoustic neuroma, Gamma Knife and Linac radiosurgery, and Linac fractionated radiotherapy, will most certainly continue as the treatments of choice. These effective therapies are much more widely available and much less expensive than proton beam.

Neuroplasticity & Neuroplasticians

Highly recommended is the important and fascinating new book by Dr. Norman Doidge, *The Brain that Changes Itself: Stories of Personal Triumph from the Frontiers of Brain Science* (Penguin, 2007). Dr. Doidge, a psychiatrist and psychoanalyst at the Center for Psychoanalytic Training and Research at Columbia University, explores the amazing new science of neuroplasticity and its practitioners, the 'neuroplasticians'. Using a case history approach, he describes the many ways in which the brain, far from being fixed or "hard-wired" like a computer, is in fact a plastic, malleable organ that is able to change and rewire itself as the need may arise. Falling by the wayside is the centuries-old doctrine of the unchanging brain, the idea that every brain function has only one hard-wired location ("one function, one location") and that if a part is damaged, the brain cannot recover the lost function. Instead, the practitioners of neuroplasticity have now shown "that children are not always stuck with the mental abilities they are born with; that the damaged brain can often reorganize itself so that when one part fails, another can often substitute; that if brain cells die, they can at times be replaced; that the many 'circuits' and even basic reflexes that we think are hardwired are not." Dr. Doidge writes in the Preface to his book: "I met a scientist who enabled people who had been blind since birth to begin to see, another who enabled the deaf to hear; I spoke with people who had had strokes decades before and had been declared incurable, who were helped to recover with neuroplastic treatments; I met people whose learning disorders were cured and whose IQs were raised; I saw evidence that it is possible for eighty-year-olds to sharpen their memories to function the way they did when they were fifty-five. I saw people rewire their brains with their thoughts, to cure previously incurable obsessions and traumas."

As might be expected, in Dr. Doidge's list of achievements by neuroplasticians, the phrase *'enabled the deaf to hear'* especially attracted our attention. Acoustic neuroma patients are always on the alert for such claims. Actually, we found (Chap.3) this to be an apt reference to Michael Merzenich, PhD, a leading researcher on brain plasticity at the University of California at San Francisco who contributed significantly to the invention and design of the cochlear implant. Merzenich is probably best known to the general public for the 2007 PBS "Brain Fitness Program." He is the founder (1996) of Scientific Learning Co. for the development of brain exercises for language-impaired and learning disabled children, and co-founder of Posit Science (2003) for computer-based training programs to enhance the cognitive abilities of older adults. But earlier in the 1960s as a graduate student at Johns Hopkins, Merzenich made major discoveries of the electrical activity of neurons by using microelectrodes and brain micromapping techniques, and during the 1970s as a professor at UCSF he applied this special knowledge to mapping the auditory cortex and assisting in the design of the multichannel cochlear implant that has allowed deaf people to hear. Dr. Doidge observes: "When Merzenich and colleagues devised the cochlear implant, a medium that translates sound waves into electrical impulses, the brain of an implant patient rewired itself to read those impulses.

This extension is possible because our plastic nervous system can integrate itself with an electronic system." Dr.Merzenich is still a neuroscience professor at UCSF. He is a member of the National Academy of Sciences and was recently honored further by election to the Institute of Medicine.

Another of the great pioneers of understanding brain plasticity is Dr. Paul Bach-y-Rita, most recently Professor of Orthopedics & Rehabilitation and Biomedical Engineering at the University of Wisconsin. Acoustic neuroma patients who have undergone neuromuscular rehabilitation for facial nerve damage are greatly indebted to this famous neuroplastician. As Dr. Doidge summarizes just one of his significant achievements: "Bach-y-Rita developed a program for people with damaged facial motor nerves. . . [He] had one of the 'extra' nerves that normally goes to the tongue surgically attached to a patient's facial muscles. Then he developed a program of brain exercises to train the 'tongue nerve' (and particularly the part of the brain that controls it) to act as a facial nerve. These patients learned to express normal facial emotions, speak, and close their eyes – one more instance of Bach-y-Rita's ability to 'connect anything to anything.'"

ANA's booklet, *The Facial Nerve and Acoustic Neuroma: Possible Damage and Rehabilitation* (2002), presents an excellent discussion of current techniques that trace back to Bach-y-Rita's important work. Regarding 'Neuromuscular Re-Education Techniques,' the booklet states (p.7): "The principle underlying this therapy is that the plasticity of the brain allows for retraining abnormalities that result from a damaged facial nerve. . . With practice, some acoustic neuroma 'alumni' with little, weak or uncoordinated facial movement on the affected side have retrained existing nerve fibers, resulting in additional or improved function." It seems fitting that facial rehabilitation specialist Jacqueline Diels, who is a member of ANA's Medical Advisory Board and lectures frequently on facial rehabilitation at ANA symposia, centers her work at the University of Wisconsin's Neuromuscular Retraining Clinic. (See, for example, Jacqueline Diels, "Current Concepts in Facial Rehabilitation after Acoustic Neuroma Surgery, in *NOTES*, Issue 97 (March 2006).

Because of his knowledge of nerve growth and understanding of brain plasticity, Bach-y-Rita argued that traditional rehabilitation exercises typically ended too soon and that both patients and doctors needed to be motivated to push harder for more significant recoveries/brain rewiring. This was the opinion also of another important neuroplastician, Edward Taub, when he began his studies on stroke at the University of Alabama in 1986. The Taub Therapy Clinic in Birmingham, Alabama, now proudly announces itself as having "the most effective stroke rehabilitation program in the world" (www.uabhealth.org). The program features Taub's Constraint-Induced Movement Therapy, whereby patients relearn how to use their more affected limbs by restricting the use of the less affected ones; and equally important, what is called 'incremental training' whereby exercises increase in difficulty over time. There is "massed practice" of exercises. The degree of success in the rewiring of patients' brains has been impressive. Dr. Doidge observes that "because the brain is plastic and capable of reorganization, we should be slow to predict how far a motivated patient with a stroke in a sensory or motor area may progress, regardless of how long the patient has lived with the disability."

The author mentions that Dr.Taub has also been involved in the search for a cure for tinnitus. Disappointingly, however, there is no discussion in the book of recent research or treatments for this increasingly common disorder. Popular current treatments such as Tinnitus Retraining Therapy (TRT) or the more recent Neuromonics essentially take advantage of the brain's neuroplasticity to retrain the brain to ignore the tinnitus. For severe cases, there has been some success with surgically implanted electrodes on

the auditory cortex. The new brain-scanning technology (PET, functional MRI) has allowed researchers to "see" tinnitus, and Dr. Richard Salvi at the Center for Hearing & Deafness at SUNY Buffalo is reportedly hopeful that a cure is near. It would have been valuable to have Dr. Doidge's review and appraisal of what's going on in the tinnitus field. (See Kate Murphy, "New Therapies Fight Phantom Noises of Tinnitus," *New York Times*, April 1, 2008; www.ata.org, the American Tinnitus Association's website, for News, Research).

At least brief mention must be made of Dr. Doidge's most striking example of how radically plastic the brain can be. This is the story of Michelle, who was born in 1973 with only half her brain, and Dr. Jordan Grafman, a research scientist at the National Institute of Neurological Disorders and Stroke (NIH), who has tried to help Michelle and explain the neuroplastic changes her brain has undergone. When the left hemisphere of Michelle's brain failed to develop, the right hemisphere took over its functions, including speech and language. How could this migration of mental function happen? It's a remarkable story told well by Dr. Doidge (Chap.11).

▲

Meeting

"Acoustic Neuroma: A Time for Surgery?"

Dr. Philip E. Stieg

Professor & Chairman, Department of Neurological Surgery

Center for Skull Base Surgery, Weill Cornell Medical College at the

New York Presbyterian Hospital

Sunday, October 11, 2009, 1-3 PM

Summit Medical Group, Lawrence Pavilion

One Diamond Hill Road

Berkeley Heights, NJ 07922

Q&A Refreshments Social Time

Directions to Summit Medical Group, Berkeley Heights, NJ

The most direct way to Summit Medical Group is via Route 78.

From **Route 78 East**, take Exit 43 (Berkeley Heights/Watchung). Follow the exit road to the light at **Valley Road** and turn left onto Valley Road. Take Valley Road to the next **light** and turn left onto **Diamond Hill Road**. Follow Diamond Hill Rd to the light at **Mountain Avenue**. Go left on Mountain Ave for a short distance to the entrance to Summit Medical Group on the left. You will see Lawrence Pavilion and parking

straight ahead as you enter. In the Lawrence Pavilion lobby, take the elevator down to 1R, the Cafe/Conference area (Note: there is another entrance to Summit Medical Group on the left just before the Mountain Avenue light. Follow the signs for Lawrence Pavilion/Parking Lots 1&2.

From **Route 78 West**, take Exit 43 (New Providence/Berkeley Heights). Bear right onto Diamond Hill Rd. Follow the instructions above for Summit Medical Group, Lawrence Pavilion.

▲