

**ANA/NJ Newsletter**  
**Volume XIV, No. 1, October 2013**

**What's New for Acoustic Neuroma,  
1993-2013**

**W**hen we emailed Dr. Kwartler to ask if he would be willing to review *What's New for Acoustic Neuroma, 1993-2013*, he replied: "Sure." No ifs, buts or maybe – Dr. Kwartler has always been ready to pitch in for acoustic neuroma. We look forward to having his thoughts about how the acoustic neuroma experience has changed for patients (and for physicians) over the past twenty years. The meeting on October 20 will be an excellent opportunity for questions and wide-ranging discussion.



For the record, we can't resist noting here that one important 'what's new' for acoustic neuroma beginning in 1993 was the establishment of the Acoustic Neuroma Association of New Jersey. The first founding meeting of ANA/NJ was held May 22, 1993, at the United Methodist Church of Lake Hopatcong in Mt. Arlington. Fourteen people attended. Led by Joanne Ridner (Mt.Arlington) and Irene Christodlous (Ledgewood), the new local chapter of ANA got off to an excellent start with increasing membership and successful further meetings in Shrewsbury (Nov 1993) and Cranford (Feb 1994). Letters were composed to be sent to doctors informing them about the new group. There was much discussion about the need to acquire a computer. But then in October 1994, because of personal involvements, both Joanne and Irene were unable to continue leading the group, and a letter went out pleading for someone to "step forward" or the group would have to disband. Fortunately, Wilma Ruskin, who had her surgery for AN in February, 1993, was able to answer the call, and a second founding of ANA/NJ took place at the home of Barbara Reed in East Brunswick on January 8, 1995. Twenty-six people attended. Wilma presided.

So that's an interesting bit of history. And it's important to add that acoustic neuroma support groups in the early 1990s were operating at the very outset of the electronic wonders so common- place today, like email, PCs, Word, Adobe, Windows, PhotoShop, label makers, home pages and internet connections. ANAUSA's board member for Public Information at that time, Harvey Baumel, first began to alert the national membership about online services, America Online and possible computer-based "Forums" in the December 1993 issue of *Notes*. "Imagine," he wrote, "that you could walk over to your computer at home and 'talk' with another acoustic neuroma patient." Still, there was no Home Page or email address for ANAUSA (estab.1981) until December 1996. ANA/NJ got along during its first years using phone, fax and the US Postal Service; the newsletter didn't begin to use Windows for formatting until the November 1996 issue. As the recent special notice in the newsletter about ANA/NJ's current need for new board members tried to suggest, it's a lot easier being a board member today than it was twenty years ago!

**Notices**

- We are happy to welcome two new members of the ANA/NJ Board of Directors: Ada Tucker (Monroe Township, Middlesex County) and Brad Zimmerman (Moorestown, Burlington County).
- Dr. Elizabeth B. Claus, PhD, MD, who is Professor and Director of Medical Research in the Yale University School of Public Health, has organized a study to determine whether or not there are genetic

risk factors that cause an acoustic neuroma. ANAUSA awarded a grant to Yale University to initiate the data collection phase of the study at the 21<sup>st</sup> National Symposium in Los Angeles. Volunteer acoustic neuroma patients were asked to complete a questionnaire and submit a saliva sample.

- An article in *The Star Ledger* reporting on the arrival of proton beam in NJ (“Cancer Breakthrough or Unproven Hope,” July 24, 2013) contrasted the “bullet-like precision” of proton beam radiation with the “buckshot approach” of “traditional radiation,” as if these were the only two choices available for patients opting to have radiation treatment. This was misleading. Acoustic neuroma patients reading the article will spot that the report needed to take into account the alternatives of Gamma Knife radiosurgery and Linac-based fractionation treatments (e.g., CyberKnife). As Dr. Lipani has described, these systems are designed to deliver radiation with extreme accuracy, targeting the tumor with minimal damage to the surrounding healthy tissue (See his article in the newsletter for June 2013).

For a description of the special nature of proton beam radiation – i.e., low ‘entrance dose’ before the tumor, high-dose energy burst (‘Bragg peak’) to the tumor volume, and no ‘exit dose’ beyond the tumor – see the FAQ section of the website for the Loma Linda University Medical Center, [www.protons.com](http://www.protons.com).

We were sorry to learn of the death of Phyllis Schreiber’s mother, **Corinne Leshnow**, a strong supporter of ANA/NJ. Phyllis Schreiber (Fort Lee, NJ) served for many years on ANA/NJ’s Board of Directors. We remember ~

### **Proton Beam Therapy**

We last reported on proton beam therapy in the September 2009 issue of the newsletter, noting at that time that area treatment centers were in the works for Robert Wood Johnson University Hospital in New Brunswick, NJ, and the University of Pennsylvania in Philadelphia. The UPenn facility (4 gantry) began operation in 2010, and completion of the RWJ center is now projected for 2014. RWJ plans to have a more compact, less costly synchro-cyclotron system (1 gantry) for treatment of pediatric patients. Meanwhile, in March 2012, a ProCure Proton Therapy Center (4 gantry) opened in Somerset, NJ. ProCure is a private healthcare company founded in 2005 to develop and operate full-service proton therapy centers. The Somerset center, which is allied with the CentraState Healthcare System and Princeton Radiation Oncology, is the fourth in ProCure’s expanding network. The opening of this center in NJ brings to eleven the total number of proton beam facilities operating in the USA. Thirteen additional facilities are expected, including one for New York City (2016?). Information about proton beam operations and professional association activities in the USA and worldwide is provided online by the Particle Therapy Co-operative Group.<sup>1</sup>

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<sup>1</sup> The website is [www.ptcog.web.psi.ch](http://www.ptcog.web.psi.ch).



Not many acoustic neuroma patients have had proton beam therapy. A PubMed search of the medical literature for 2002-2007 showed proton beam treatment for AN in 6.8% of published articles, compared to 49.2% for Gamma Knife and 35.6% for linear accelerator/Linac.<sup>2</sup> Proton Beam (PB) is a highly complex and expensive form of radiation therapy that has only recently begun to expand in patient treatment capacity in competition with existing Gamma Knife and Linac radiation systems.

In the USA before 2006 there were only a couple of places offering opportunities for proton beam treatment – Loma Linda University Medical Center in southern California and Massachusetts General Hospital in Boston. Only a few acoustic neuroma patients were treated. In 2002, Loma Linda reported on 30 acoustic neuroma patients treated during 1991-1999 by conventional fractionated proton beam radiotherapy.<sup>3</sup> In 2003, Massachusetts General reported on 88 acoustic neuroma patients treated during 1992-2000 by proton beam radiosurgery.<sup>4</sup> We notice that proton beam treatment was being given either as single-session radiosurgery or multiple-session radiotherapy. In 2009, however, Tygerberg Hospital in South Africa published a retrospective study evaluating 51 acoustic neuroma patients treated at its proton facility during 1993-2008 by hypofractionated proton beam radiotherapy.<sup>5</sup> Three different modes of proton beam treatment for acoustic neuroma? This complicates making comparisons between proton beam and other radiation systems.

Below is data for the different modes of proton beam treatment, compiled using PubMed abstracts of the three reports cited in our footnotes. Tumor control rates are shown to be excellent. Facial and trigeminal nerve function preservation rates are also seen to be very good to excellent. Disappointing, on the other hand, are the low ‘useful hearing’ preservation rates of 31 to 42%. In contrast, Gamma Knife radio-surgery has attained hearing preservation rates of 60-70%, and a rate of 76% is being reported for CyberKnife hypofractionation. Loma Linda stated in 2002 that a reduction in tumor dose was being evaluated. A recent Cleveland Clinic review of the data for proton beam for AN has recommended efforts to reduce the dose to critical structures.<sup>6</sup>

### Data for Proton Beam

- **Loma Linda, 2002: Conventional Fractionation**

- 30 acoustic neuromas
- Rad. Dosage, 54-60 Gy in 30-33 fractions
- Mean Follow-up, 34 mon
- Tumor Control, 100%
- Facial Nerve Preservation, 100%
- Trig. Nerve Preservation, 100%
- Useful Hearing Preservation, 31%

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<sup>2</sup> M.K.Bassim et al, “Radiation Therapy for the Treatment of Vestibular Schwannoma: a Critical Evaluation of the Literature,” *Otol Neurotol*, 31 (2010).

<sup>3</sup> J.M.Slater et al. “Fractionated Proton Beam Radiotherapy for Acoustic Neuroma,” *Neurosurgery*, 50 (Feb 2002).

<sup>4</sup> D.C.Weber et al, “Proton Beam Radiosurgery for Vestibular Schwannoma: Tumor Control and Cranial Nerve Toxicity,” *Neurosurgery*, 53 (Sept 2003).

<sup>5</sup> F.J.Vernimmen et al, “Long-term Results of Stereotactic Proton Beam Radiotherapy for Acoustic Neuromas,” *Radiother Oncol*, 90 (Feb 2009).

<sup>6</sup> E.S.Murphy & J.H.Suh, “Radiotherapy for Vestibular Schwannomas: a Critical Review,” *Int Jour Radiat Oncol Biol Phys*, 79 (Mar 2011).

- **Massachusetts General, 2003: Radiosurgery**

- 88 acoustic neuromas
- Rad. Dosage, 10-18 Gy in 1 fraction
- Mean Follow-up, 38.7 mon
- Tumor Control, 95%
- Facial Nerve Preservation, 91.1%
- Trig. Nerve Preservation, 89.4%
- Useful Hearing Preservation, 33.3%

- **Tygerberg Hospital, 2009: Hypofractionation**

- 51 acoustic neuromas
- Rad. Dosage, 26 Gy in 3 fractions
- Mean Follow-up, 60-72 mon
- Tumor Control, 98%
- Facial Nerve Preservation, 90.5%
- Trig. Nerve Preservation, 93%
- Useful Hearing Preservation, 42%

A departmental study paper by Dr Jerry D. Slater, the chair of Loma Linda's Department of Radiation Medicine, helps to explain the various treatment strategies used during 1990-2010.<sup>7</sup> Dr Slater wrote (summer 2012) that beginning in 1994 clinical emphasis was on expanding treatments to a variety of anatomic sites and developing appropriate treatment strategies. It was important to study the efficacy of proton therapy over a broad range of medical conditions and to establish if proton therapy and existing radiation treatments were equally effective. "These studies continue today: priority is given to patients on clinical trials, and patients are accepted outside of clinical trials only when beam time permits. . . For many anatomic sites, treatment strategies evolved over time, as experience and technology accumulated. Investigations proceeded on the premise that ionizing radiation from any source will destroy targeted tissue if the total dose is high enough. The main consideration was to determine whether necessary total doses could be delivered without causing unacceptable permanent damage to normal tissues."

In this study paper, Dr Slater indicated Loma Linda's preference for using conventional fractionation to treat acoustic neuromas, but he also observed a growing interest in his department with dose escalation and hypofractionation. He wrote: "[Loma Linda] radiation oncologists are examining hypo-fractionation as a way to reduce treatment time and costs, provided that control rates are maintained and side effects do not increase. Given that costs such as beam time are a fixed part of each treatment fraction delivered, hypo-fractionated regimens should lead to cost reductions. These reductions, however, will not be permitted to compromise patient safety."

### **Treating Chronic Tinnitus: A New Protocol\***

Berthold Langguth, MD, PhD, is a neurologist and professor of psychiatry at the University of Regensburg, Germany. A recognized leader in the field of tinnitus research, Dr. Langguth was recently awarded a research grant by the American Tinnitus Association for study of "Combined Transcranial Magnetic Stimulation in Treatment of Chronic Tinnitus Using Double Cone Coil."<sup>8</sup> The following description of the research project is excerpted from a progress report published in the Summer 2012 issue of *Tinnitus Today*.<sup>9</sup>

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<sup>7</sup> "Clinical Proton Therapy at Loma Linda University Medical Center," (Summer 2012), online at [www.three.usra.edu/articles/LLUClinical.pdf](http://www.three.usra.edu/articles/LLUClinical.pdf).

<sup>8</sup> See [www.ata.org/research/ata-funded](http://www.ata.org/research/ata-funded).

<sup>9</sup> A. Lehner, M. Schecklmann & B. Langguth, "rTMS for the Treatment of Chronic Tinnitus: Optimization by Stimulation of the Cortical Tinnitus Network," in *Tinnitus Today* (Summer 2012), 12-14.



Scientists have dealt with the causes of tinnitus for many years now and although we have still not found the key to turning it off, many important insights concerning its generation and manifestation were gained during the past decade. Some years ago, scientists realized that the long-held assumption that tinnitus was an inner-ear issue was not truly the case. They began to focus on the auditory pathway – the route starting in the ear and leading to the AC [*auditory cortex*] in the brain.

Realizing the relevance of the brain for generation and maintenance of tinnitus was a milestone in tinnitus research and brought many scientists to examine tinnitus-related alterations within the auditory pathway. Studies which analyzed the structure and activity of auditory brain regions found abnormalities. For example, the AC is more active in tinnitus patients. This led to the idea that if the hyperactivity could be reduced, this should have an effect on the tinnitus percept. As a result, new treatment approaches were developed which target this hyperactivity of the AC.

One of these treatment approaches is *repetitive transcranial magnetic stimulation* [rTMS], . . . a technique which applies strong magnetic fields to the brain for modulating neural activity. The magnetic fields are produced within a coil which is placed on the scalp . . . and are able to influence the activity of *neurons* lying beneath the coil. If placed over the AC, rTMS is assumed to normalize the altered AC activity and ease tinnitus complaints. For this purpose, rTMS is usually applied on 10 consecutive working days with each of the sessions lasting about 30 to 45 minutes. In recent years, many studies have shown that rTMS is able to reduce tinnitus severity in some patients. The effects of this treatment are only small to moderate however.

This is where the second important milestone of tinnitus research comes into play. Recent studies suggest that in order to fully understand the neural correlates of chronic tinnitus it is not enough to solely concentrate on altered activity within the auditory pathway. Rather, non-auditory brain areas should be additionally taken into account. It is understood that a sound -- no matter if it is a “normal” sound or tinnitus --only enters consciousness if non-auditory areas are involved in its processing. Some studies have found alterations of the activity within these non-auditory structures in patients with tinnitus.

Currently, this theory of both auditory and non-auditory brain areas being important for tinnitus is being refined by some scientists. The idea is emerging that we should not concentrate on the activity within each of these brain regions separately, but instead focus on a “tinnitus network” of interconnected auditory and non- auditory brain areas which exert influence on each other. This could be the reason for the limited effects of rTMS on the AC. While the AC is treated with rTMS, the remaining brain areas of the tinnitus network maintain their altered activity. Due to the connections within the network, the auditory cortex is still influenced by the non-auditory sites, narrowing the benefit of rTMS.

The idea of a network of interconnected brain areas being involved in the tinnitus percept allows for a promising refinement of rTMS treatment. If several core regions of this network are targeted by rTMS, a more pronounced reduction of tinnitus severity might be possible than by exclusive stimulation of the AC. Therefore, our study examines a new rTMS stimulation protocol which involves three stimulation sites instead of only one. In the past, rTMS was applied over the *temporal cortex* of the left (or the right) hemisphere as this is where the AC is located. In our study, the *temporoparietal cortex* of both hemispheres plus the left *frontal cortex* are stimulated. . . By targeting these three stimulation sites, several nodes of the tinnitus network are covered.

In a pilot study, we have already applied the new rTMS protocol in some patients with chronic tinnitus. Multisite stimulation was well tolerated by all patients who were treated and no serious side effects were observed. Compared to classical stimulation, the new multisite stimulation protocol led to a more pronounced and longer lasting improvement of tinnitus severity. This better long-term effect is a very promising result which underscores the relevance of network stimulation and highly encourages us to explore both the clinical and neurobiological effects of the new protocol in more detail.

\*Reprinted in part from the Summer 2012 issue of *Tinnitus Today* with permission from the American Tinnitus Association.

### **Treating Tinnitus: A Different Approach\***

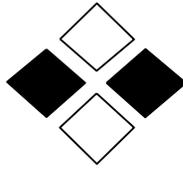
Dr. Debara Tucci, a specialist in otolaryngology at Duke University in Durham, NC, responded differently to the key idea that both auditory and non-auditory brain areas are important for tinnitus.

Dr. Tucci is principal investigator at Duke Integrative Medicine for a clinical trial “to determine if an integrative medicine approach [mindfulness based stress reduction, acupuncture] which targets treatment of the non-auditory aspects of tinnitus suffering [anxiety, depression] is more effective in alleviating tinnitus symptoms when added to current therapies, compared to [using current therapies] alone.” The clinical trials proposal states: “Based on prevalence data from tinnitus sufferers who seek treatment and the known percentage who do not respond to commonly used therapies, we estimate that 1.2 million individuals are not able to benefit at all from current, widely used treatment strategies. [An integrative medicine] strategy to augment those currently used could empower patients to exert control over their tinnitus symptoms with-out the use of medications, expensive devices such as the Neuromonics device, or extended programs such as TRT [Tinnitus Retraining Therapy].” The Duke study is in collaboration with the National Institute on Deafness and Other Communication Disorders (NIDCD).



\*Source: “Preliminary Clinical Trials of an Integrative Therapy with Severe Tinnitus,” ClinicalTrials.gov, NCT01480193, Estimated completion date Oct 2013. See also [www.dukeintegrativemedicine.org/research](http://www.dukeintegrativemedicine.org/research).

**See Next page for information on October Chapter Meeting**



Fall 2013 Chapter Meeting

**“What’s New for Acoustic Neuroma?”**  
**(A Look at Two Decades of Change, 1993-2013)**

**Jed A. Kwartler, MD**

Otologist/Neurotologist, Summit Medical Group

Sunday, October 20, 2013

1-3:30 pm

Summit Medical Group

Lawrence Pavilion, One Diamond Hill Road

Berkeley Heights, NJ 07922

A wide-ranging presentation/discussion of changes in the acoustic neuroma experience for both doctors and patients over the past twenty years.

Refreshments Social Time

**Directions to Summit Medical Group**

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The most direct way to the Summit Medical Group facility in Berkeley Heights is via Route 78.

From Route 78 East, take Exit 43, Berkeley Hts/Watchung. Follow the exit road to the light at Valley Rd and turn left onto Valley Rd. Go on Valley Rd to the first light and turn left onto Diamond Hill Rd.

Follow Diamond Hill Rd to the light at Mountain Ave. 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 Café/Conference area. (Note: there is another entrance to Summit Medical Group on the left just before the Mountain Ave light. If you pull in there, just follow the signs for Lawrence Pavilion/Parking Lots 1&2.

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

