

**ANA/NJ Newsletter**  
**Volume XIII, No. 3, March 2013**

**ANA/NJ Mini-Conference**  
**October 28, 2012**

Seventy-five people were present at ANA/NJ's 2012 Mini-Conference held at the Conference Center, JFK Medical Center, in Edison, NJ. The good attendance was especially remarkable keeping in mind that "Sandy" the hurricane threatened to blow into NJ at the time. Very welcome as an attendee at the conference was Jeffrey Barr, the recently elected President of the Board of Directors of ANAUSA for 2012-2014, who Wilma Ruskin was pleased to introduce during the opening of the morning session. Jeff resides in Livingston, NJ, and has been wait-and-watch since 2009. His remarks before the group thanking Wilma for her care and assistance during his 'times of trouble,' and praising the work of ANA/NJ overall, were most appreciated and encouraging. He also took the opportunity to call attention to important goals of the national association for the coming years, including a new ANA Patient Survey. (See *ANA Notes*, Sept 2012)



ANA/NJ vice president Dave Belonger spoke next to introduce Dr. Joseph Landolfi (NJ Neuroscience Institute, JFK), the moderator of the morning session's "Doctor's Panel: Acoustic Neuroma – Diagnosis & Treatment Options." As seen in the photo, the panelists (from left to right) were Dr John

Lipani (Cyberknife), Dr James Liu (Surgery Approaches), Dr Richard Hodosh (Wait-and-Watch) and Dr Joseph Landolfi (Gamma Knife). Dr. Landolfi asked the panelists to describe briefly their roles in the treatment of AN. He then opened the session for Q&A.



In response to a wide range of questions, the following observations (in summary form) were made by the panelists:

- Endoscopic surgery is not a widely accepted treatment for AN and is unlikely to ever become a standard procedure. Use of the endoscope for what is called 'assisted' surgery has limited value.
- Proton beam radiation treatment sites have increased in number recently. Currently there is no data to suggest proton beam radiation treatment is a better choice than Gamma Knife or Linac for acoustic neuroma.
- Cystic tumors do not respond well to radiosurgery. Surgical treatment is indicated.
- The tumor control rate for Gamma Knife radiosurgery is about 98%; hearing preservation rate about 73%. Patients should anticipate some reduction in hearing, possibly some transitory nerve reaction. The risk of radiation-induced malignancy is exceedingly small. Some degree of tinnitus may be a side-effect.

Continuing fatigue was not considered to be a directly related outcome; such fatigue may be a result of patient energy expenditure due to balance issues and/or hearing problems.

- CyberKnife allows for fractionated radiotherapy whereby the total radiation dose is delivered in fractions over a period of time. This may be helpful in preserving normal tissue, protecting good cells while destroying bad cells; and it may be helpful as well for hearing preservation (present percentage rate is in the high 70s). On the other hand, low dose fractionated treatments may compromise tumor control, i.e., the goal of stopping tumor growth. These matters are still under investigation.
- The panelists addressed the question of tumor regrowth and were in agreement that regrowth is always a possibility regardless of the type of treatment. Every tumor has its own ‘personality’ and needs careful watching by periodic MRIs. It was cautioned that patients should make sure that MRIs are read by the treating physician and not just by the radiologist.
- Studies continue to look for medicines to treat brain tumors. The drug ‘Avastin,’ for example, was FDA approved for its potential to stop tumor growth by inhibiting tumor blood vessel formation.
- Many considerations influence the choice of treatment for acoustic neuroma: symptoms, size of tumor, patient age, occupation, preop hearing status, tumor location. Surgery (three approaches are available) may be preferred by patients who want the tumor ‘out.’ Younger patients may be more concerned over possible long-term effects of radiation treatment. For physicians and patients, the treatment selection process has evolved and become more flexible in recent years.

After a good lunch, the afternoon session began with Dr. Michael Rosenberg’s address entitled “Visual



Vestibular Mismatch Syndrome,” an examination of the sorts of dizziness problems encountered by AN patients (light-headedness, imbalance, vertigo) and ways patients can help the brain compensate for a vestibular system disorder. Dr Rosenberg reviewed the anatomy of the vestibular system and described patient rehabilitation procedures. He recommended that rehab should be done a bit at a time; the ‘no pain, no gain’ approach does not work well, he said; medications are not as helpful as exercise; and psychological intervention can be useful. Cases of post-treatment tiredness/fatigue, he pointed out, can be related to the great amount of energy expended by the patient in compensating for a vestibular system disorder. Dr Rosenberg responded to a

variety of questions following his presentation.

Two concurrent workshops were scheduled to complete the afternoon session:

Workshop No.1 , “Advances in Hearing Technology,” was conducted by Elizabeth (‘Liz’) Cook, who is the chief audiologist of Total Hearing Care in Morristown, NJ.

The workshop featured the description and demonstration of the ‘Ponto’ Bone Anchored System for single-sided deafness (SSD) developed by Oticon Medical. The Ponto and the Baha (Cochlear Americas) are two leading (and competing) implant systems for SSD. On hand to assist Liz was Oticon Medical representative Alison Sabar, who many at the conference met earlier at the Oticon table in the main room.





Workshop No. 2, conducted by Joshua David O'Brien, who is the founder of the Mindfulness Community of Central Pennsylvania, was an introduction to the practice and benefits of meditation for coping with stress, anxiety, worry, pain, depression. Joshua's demeanor before the group was itself a calming influence as he presented instruction for a 20-minute per day meditation antidote to what he described as our 'Flight, Fight or Freeze' inbred reaction to worrisome situations. He recommended we Google *medical meditation* for more information about the art and benefits of meditation.

### *"Medical Professionals Who Have Had an Acoustic Neuroma"*

#### A Proposed Panel Discussion

Are you a doctor, nurse, audiologist or other medical professional who has experienced an acoustic neuroma? Would you like to be a member of a proposed discussion panel for a meeting of ANA/NJ? If you are interested, please contact Wilma Ruskin, president of ANA/NJ, at 609-799-4442 or email [ananjinc@aol.com](mailto:ananjinc@aol.com).

### Notices

- Welcome to two new members of our Medical Advisory Board! Dr. John D. Lipani is founder-director of Princeton Neurological Surgery & Brain and Spine Radiosurgery Institute. He is a neurosurgeon with extensive training and experience in both CyberKnife and Gamma Knife technology. Dr. Michael L. Rosenberg is director of Neurology and Neuro-ophthalmology at the NJ Neuroscience Institute, JFK Medical Center. He is Professor of Neuroscience at Seton Hall University.
- Valley Hospital in Paramus, NJ, now offers the Leksell Gamma Knife 'Perfection' system for stereotactic radio- surgery of acoustic neuroma. The Co-Director of the Gamma Knife Center is Anthony D'Ambrosio, MD. For information, go to [www.valleyhealth.com](http://www.valleyhealth.com) or phone 201-634-5677.
- Lorraine Steefel, RN, MSN, is the author of *What Nurses Know... Chronic Fatigue Syndrome* (NY; Demos Health, 2012). She is adjunct assistant professor in the Doctor of Nursing program at UMDNJ School of Nursing, Newark, NJ.

## Save the Date

ANA 21<sup>st</sup> National Symposium  
August 9-11, 2013 Los Angeles, CA

For more information, go to [www.ANAUSA.org](http://www.ANAUSA.org)

***HealthNewsReview.org***  
**Keeping Tabs on Health News Reporting**

Funded by the Informed Medical Decisions Foundation based at Dartmouth Medical School, the website *HealthNewsReview.org* evaluates consumer health news stories produced by major U.S. news organizations such as *The New York Times*, *Washington Post*, *Time*, *MSNBC.com*, *HealthDay*, *WebMD*, *USA Today* and *CNN.com*. The publisher is Gary Schwitzer, a noted and respected specialist in health care journalism (See [www.reportingonhealth.org](http://www.reportingonhealth.org)).

Schwitzer and his team of reviewers use ten review criteria to grade the quality of health care stories dealing with medical treatments, tests, products and/or procedures. They ask:

- 1) Does the story adequately discuss costs?
- 2) Are benefits adequately explained?
- 3) Are potential harms adequately explained?
- 4) Is evidence for the story critically evaluated?
- 5) Does the story exaggerate a condition or its prevalence?
- 6) Does the story use independent sources and are conflicts of interest indicated?
- 7) Does the story compare existing alternative approaches?
- 8) Is current availability made clear?
- 9) Does the story establish the true novelty of a 'new' treatment, test, product or procedure?
- 10) Does the story rely solely or largely on a news release?

These criteria, it should be noted, are modeled upon the news story evaluations developed by two pioneer websites in the field, *Media Doctor Australia* and *Media Doctor Canada*.

*HealthNewsReview.org* provides a convenient search box for its Story Reviews and for Gary Schwitzer's informative Health News Watchdog blog. The website does not give medical advice. Its basic mission is to (a) improve the quality of health care news supplied to consumers, and (b) help consumers to "critically analyze claims about health care interventions."

**Thinking About Hearing Devices for SSD,  
Single-Sided Deafness**

We've come a long way since the ear trumpet, a hearing device in use during the 19<sup>th</sup> and well into the first decades of the 20<sup>th</sup> century. Even a quick glance at the following two illustrations will suggest some problems with this device. For instance, it's been said that the ear trumpet



was, at one and the same time, both too small and too visible. It was too small to funnel and amplify sound most effectively and it was too visible to be altogether satisfactory socially. People in those days were trying to hide such sound gathering devices in hats, canes and even behind beards. To help socially, ear trumpets would be made in impressive gold or silver or with intriguing designs or in special colors. A sampling of what was available at the time can be viewed online by scrolling through Neil Bauman's Hearing Aid Museum. But marketing gimmicks couldn't compensate for the ear trumpet's awkwardness and minimal

sound amplification. Really, since the cupped hand, the device wasn't the greatest 'leap forward' in the history of hearing aids.



For people today with single-sided deafness (SSD) there's a lot more help available than an ear trumpet would provide (even if one could be found). Consider first of all the Baha, the innovative bone conduction hearing system -- titanium implant, external abutment, detachable sound processor -- illustrated here in one of its most recent models. The Baha originated in 1952 in Gothenberg, Sweden,



when Dr. Per-Ingvar Brånemark, the “father of modern dental implantology,” discovered how living bone would fuse with titanium metal by a process he called osseointegration. Dr. Brånemark collaborated with colleagues in the ENT department at Sahlgrenska University Hospital in Gothenberg to develop the prototype of the Baha, and in 1977 the first three patients were implanted with titanium fixtures to the skull. Vibrational sound was transmitted successfully via bone conduction directly to the cochlea bypassing the auditory canal and middle ear. No head band or in-the-ear fittings were required. Ear canals were left open. Sound quality was more natural than with conventional air conduction aids. As new technology and engineering refinements were progressively added over the years, the Baha system came to be the ‘gold standard’ for bone conduction hearing for SSD. The system was introduced in the US in 2002 by Swedish manufacturer Entific Medical Systems. Since 2005, the Baha has been made and developed further by Cochlear Americas headquartered in Centennial, CO. The third generation of the Baha sound processor, the BP100, was launched in 2009.

The year 2009 was also when the major Danish hearing aid company Oticon brought out its competing bone anchored hearing system, the Ponto Pro. As with Cochlear’s Baha, Oticon’s Ponto requires minor surgery for the titanium implant and there are no in-the-ear pieces. A most noticeable external feature difference is Oticon’s teardrop shaped sound processor, which has been said to be ‘sexier’ than the

BP100 rectangle. Of course, there’s a lot more to deciding on a hearing system than the look of the device. These are very sophisticated and quite expensive systems that require the help of hearing specialists. Potential users will want to ask for the trial headband to test the sound processor in different hearing environments prior to surgery. Googling the internet in advance for Baha vs. Ponto Pro is a good idea. ANA’s Discussion Forum will be found to have valuable postings by recent users of the two devices.



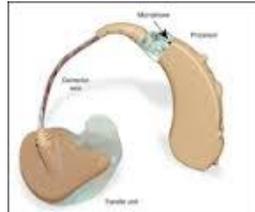
Anyone bothered by the external abutment feature of the Baha and Ponto may wish to check out two other bone conduction systems, the Sophono and the Bonebridge. These require a surgical implant, but are abutment-free through the use of magnets to affix the external sound processor to the implant.

For AN patients with SSD who are not keen on having another surgery, there are alternative devices for bone conduction sound transmission. The latest is SoundBite (Sonitus Medical), which transmits vibrational sound via the teeth. A tiny microphone (see Right) placed in the deaf ear canal receives and sends sound to a transmitter worn behind the same ear. The sound then goes wirelessly to a device fitted



in the mouth (see Left) that produces vibrational sound for bone conduction via the teeth directly to the cochlea. The system requires visits to a dentist for a check on oral health and to make a dental impression for customizing the mouthpiece. Potential users can try a demo.

TransEar (Ear Technology Co.) is a second non-surgical bone conduction hearing system available for SSD. The TransEar looks like a conventional BTE hearing aid, but the custom shell that fits into the ear canal of the deaf ear has “an oscillator that makes contact with the bony portion of the ear canal. When sound is ‘received’ on the side of the non-functioning ear, it’s converted to mechanical energy that drives



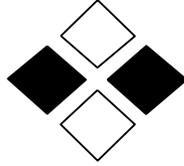
the oscillator. Those signals are then transferred via the bones of the skull to the cochlea in the opposite ear.” The shell in the canal is made tight for good bone conduction. A trial period is available.

Finally, it must be added that a bone conduction hearing system is not essential for coping with SSD. Two past presidents of ANA, Agnes Garino and John Zipprich, have shown this to be the case by their recent ‘Voyages’ articles in the association’s *Notes* (December & June, 2012, respectively). Both relate how they spent many years searching/waiting for a satisfactory solution to their ‘hearing issue.’ Both were ideally positioned for keeping up with advances in hearing devices. And, interestingly, both opted finally for a CROS air conduction hearing aid by Phonak (see below). The CROS (or BiCROS if there



is some hearing loss in the better ear) requires a device for each ear: a microphone/transmitter for the deaf ear, and a receiver/amplifier for the normal ear. Sound is transmitted wirelessly from the deaf ear to the normal ear. A device in each ear? John Zipprich writes that he said to his audiologist, “Sure, let’s try it.” And there you go!

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Spring 2013 Chapter Meeting

***“A Time to Share”***  
***Open Meeting for Patients, Family & Friends***

Sunday, April 7, 2013

1-3:30 pm

Mercer County Library System

Lawrenceville Branch

2751 Brunswick Pike (Route 1 South)

Lawrenceville, NJ 08648

A time to ask questions and discuss problems with other acoustic neuroma patients.

You do not need to be a member of ANA/NJ to attend.

Refreshments will be served.

\*Note: A representative of Sonitus Medical will be in attendance to answer questions about SoundBite, the bone conduction hearing system designed for SSD that transmits sound via the teeth.

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**Directions to the Library**

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**From North Jersey:** Take Route 1 South. After the I-295 overpass there will be a traffic light at Franklin Corner Rd. Stay to the right onto Business Route 1 and make a right turn at the next light onto Darrah Lane. The library is on the right.

**From Trenton:** Take Route 1 to the Whitehead Road Exit. Make a left onto Whitehead Rd and follow until the traffic light. Make a right onto Business Route 1 and continue North about one mile. Immediately after the third traffic light, move into the jug-handle to cross Route 1 onto Darrah Lane. The Library is on the right.

**From Eastern NJ:** Take I-195 West to I-295 North. Exit at Route 1 South. Follow the “From North Jersey” directions above.

**From South NJ:** Take I-295 North. Exit at Route 1 South. Follow the “From North Jersey” directions above.

