ANA NJ
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Acoustic Neuroma Association

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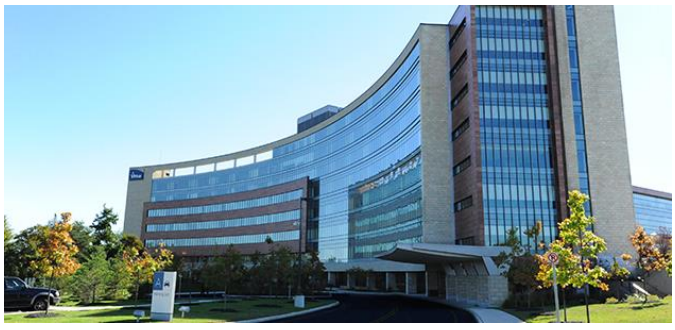

ANA/NJ Fall Meeting, Voorhees, NJ
October 14, 2018

Eighteen patients and caregivers, including six board members, attended our Fall meeting held at the Virtua Hospital in Voorhees, NJ. We thank our vice president Dave Belonger for initiating arrangements with Virtua Hospital, and Michele Spack, administrative assistant at Virtua, for helping so well with scheduling and the details of room set up. A special attendee introduced at the meeting was Iryna Lutsenko, a post-treatment acoustic neuroma patient who has just recently become Support Group Leader/Facilitator for ANA's Southern NJ Group. Attention was called to this group's first meeting scheduled for October 21 in Cherry Hill.

Our meeting at Virtua in Voorhees was an open discussion for patients and caregivers to share their personal and family experiences with acoustic neuroma. To summarize briefly: (1) A Wait-and-Watch patient reported that his 1.4 cm tumor has stopped growing, although he understands that his hearing loss (now down 40%) may nevertheless continue. (2) A patient described her CyberKnife experience for a 2.1 cm tumor; she had trouble with the plastic mask used to hold her head steady; there was some transient swelling of the tumor following the treatment. (3) A patient (2.9 cm tumor) who reported serious post-surgery problems with balance, fatigue and 'brain fog' at our October 2016 meeting noted further problems with sleep, mood swings, memory and nausea; he continues to consult with doctors and keep active as far as possible. (4) A caregiver asked for advice for her stepdaughter regarding continual headaches following retrosigmoid surgery; acupuncture and B^2 vitamins have been tried; materials dealing with causes of such headaches and possible remedies will be mailed to her. (5) A new patient discussed how her tumor failed to be spotted on a first MRI (one without gadolinium contrast) in 2012; the tumor is now 1.4 cm and she is Wait-and-Watch with OK hearing and some tinnitus; she is considering radiation treatment; she has been interested to learn of Dr. Stankovic's research at Harvard Medical for the drug *mifepristone* which may act to control tumor growth (See the Newsletter, October 2018). (6) A case of subtotal surgery with a 2mm 'residual' was reported; initial tumor size was 3.5 cm in 2016 with symptoms of hearing loss and significant vertigo; surgery was in 2017; radiation treatment for the residual is anticipated (See "Thinking about Residual Tumor" in the Newsletter, Sept 2015 & April 2016). (7) Finally, an 80-year-old patient discussed a case of hydrocephalus following her successful Gamma Knife radiosurgery. Since treatment the 2.1-2.3 cm tumor has "gone"; the excessive CSF (cerebrospinal fluid) was successfully drained using a shunt.

Many thanks to all attendees for a very informative meeting with lively discussion.

Notices

● In case you missed it, on January 24 on our Facebook website, Wilma posted the following important message for all ANers: "Good morning all. Anyone out there want to become an acoustic neuroma star? Our Board members are discussing our next symposium for April of 2020, and are looking for patients or friends or family members who would be interested in helping us with the planning. Please let me know: ananjinc@aol.com. Thank you!"

● Drs. Mathew L. Carlson and Michael J. Link (Mayo Clinic) have issued some preliminary findings (Fall 2018) resulting from their continuing study of "Prospective Quality of Life in Patients with Acoustic Neuroma." For a cohort of 539 VS patients from 1998 to 2008 with tumors less than 3.0 cm, the study found that differences in reduced quality of life (QOL) almost 8 years after either diagnosis or treatment were really very small regardless of whether tumor management was by surgery, radiation or simply observation. "Even more intriguing," the researchers report, "we found that the main symptoms that drive

a reduced QOL in VS patients are primarily ongoing dizziness, followed by headache, followed by tinnitus, with facial weakness and hearing loss actually coming in fourth and fifth place, respectively." Treatment modality did not predict which patients would have these bothersome symptoms. "For example, the only predictor for long-term dizziness was the presence of severe dizziness at the time of diagnosis – treatment did not really positively or negatively impact it."

● Researchers at the Cleveland Clinic have used data from the Central Brain Tumor Registry of the Unites States in Hinsdale, IL, to calculate that over 3,300 vestibular schwannomas (VS) are diagnosed per year in the US. From 2004 to 2010 there were 23,729 newly diagnosed VS in the US. The overall incidence of VS was 1.09 per 100,000 of population. "Incidence increased with age to a peak of 2.93 per 100,000 in the 65-74 year old age group. Overall, there was no difference in incidence by gender. Incidence is higher in Asian Pacific Islanders and lower in African Americans and Hispanics." (See V.Kshettry et al, "Incidence of Vestibular Schwannomas in the United States," *Jour Neurooncology*, Vol 124, Sept 2015.)

"A Shift Toward Conservatism"

We read with great interest the report by Mayo Clinic researchers entitled "The Changing Landscape of Vestibular Schwannoma Management in the United States – A Shift Toward Conservatism."[1] The 'Results' section of the report states:

A total of 8330 patients (average age 54.7 years, 51.9% female) were analyzed. The mean incidence was approximately 1.1 per 100,000 per year and did not vary significantly across time; however, from 2004 to 2011 there was a statistically significant decrease in tumor size category at the time of diagnosis. Overall, 3982 patients (48%) received primary microsurgery, 1978 (24%) radiation therapy alone, and 2370 (29%) observation. Within the microsurgical cohort, 732 (18%) underwent subtotal resection, and of those, 98 (13.4%) received postoperative radiation therapy. [Surgical treatment] was more common in younger patients and larger tumor size categories. Management trend analysis revealed that microsurgery was used less frequently over time, observation was used more frequently, and the pattern of radiation therapy remained unchanged. [A linear regression equation] was applied to predict future management practices. These data predict that by 2026, half of all cases of VS will be managed initially with observation.

This prediction that 50% of cases of VS will be managed initially with observation (Wait-and-Watch) by 2026 may seem improbable, but it is in line with trends reported by neurosurgeons, as well as current patient concerns for maintaining quality of life. In ANA's webinar series, for example, Dr.Ted McRackan (March 2018) noted how he already recommends observation for over 50% of his patients; and Dr. John Oghalai (November 2018) reported that 40% of his patients never need treatment; 25% opt for radiation; and 35% for surgery.

What are some of the reasons for the "Shift Toward Conservatism?"

(1) As shown by the valuable series of ANA Patient Surveys (1998, 2007-08, 2012, 2014), tumor size at diagnosis has decreased significantly.[2] The percentage of tumors 1.5 cm or less rose from 23% in

[1] M.L.Carlson, M.J.Link et al, *Otolaryngol Head Neck Surgery*, Vol. 153(3) (September 2015). Mayo Clinic School of Medicine, Rochester, Minnesota, USA.

1998 to 47% in 2014. For the ANA 2014 Survey, 63% of patients who chose Wait-and-Watch management said that they did so because their tumors were less than 1.5 cm. Researchers at the Gentofte University Hospital in Copenhagen have been tracking the trend in Denmark. In 2004 they reported: "The size of diagnosed tumors has decreased from a median of 35 mm in 1979 to 10 mm in 2001.[3]

(2) Notably in Denmark, where 40% of 1,818 patients were allocated to observation by MRI during 1975-2005, researchers have continued to publish valuable data on the growth patterns of sporadic VS that support initial observation of small tumors. An MRI six months after tumor diagnosis can identify tumors either likely to continue growing or suitable for observation. For the majority of small intrameatal [in the canal] tumors, the recommendation has been observation with yearly MRI for 5 years, followed by MRI every other year for 4 years, followed by MRI after 5 years, ending the observation if no growth has occurred. A caution is that late growth after five years of quiescence may occur.[4]

(3) By 1991, the superior imaging by MRI replaced X-ray computerized tomography (CT), which was in use since 1971 despite its ionizing radiation risks. The National Institutes of Health's consensus statement on *Acoustic Neuroma* (December 1991) stated: "MRI now is regarded as the most definitive study that can be performed, and is capable of revealing vestibular tumors as small as a few millimeters in diameter. The use of MRI with contrast enhancement has resulted in the identification of patients with very small, relatively asymptomatic VS for whom the natural history is still not known. Conservative management may be appropriate for these patients."[5]

(4) Doctors have responded positively to patient concerns over preserving Quality of Life (QOL) as far as possible during the treatment process.[6] In the ANA 2014 Patient Survey, 77.2% of patients who chose to Wait-and-Watch rather than have surgery or radiation said they did so because of their doctor's advice.

(5) Over the years, VS patients have become much more knowledgeable about options for the management of their tumors. The Internet has provided easy access to information about VS, and a strong network of patient support groups has developed in the United States.

There's an excellent personal account and evaluation of the Wait-and-Watch experience by Carol Krucoff entitled "The Waiting Game: Why I Let My Brain Tumor Go Untouched for 10 Years."[7] Her 3 mm asymptomatic VS was discovered incidentally in 2003 when she was 50 years old; she allowed it to grow to 6 mm by 2006; and to 12 mm by 2013, at which point she intervened to have Gamma Knife radiosurgery. Her VS was still asymptomatic, but she decided that with any further growth there was "a strong likelihood of negative effects on her hearing and facial nerves." Carol observed that the 'waiting

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[2] The ANA 2014 Survey is online in full at ANA-USA.org. A brief review of the survey is in our Newsletter for April 2018. See also J.Patel et al, "The Changing Face of Acoustic Neuroma Management in the USA: Analysis of the 1998 and 2008 Patient Surveys from the Acoustic Neuroma Association," *British Journal Neurosurg*, Vol. 28 (January 2014).

[3] S.Stangerup et al, "Increasing Annual Incidence of VS and Age at Diagnosis," *Jour Laryngol Otol*, Vol. 118 (August 2004).

[4] S.Stangerup et al ,"The Natural History of VS," *Otol Neurotol*, Vol 27 June 2006). See "Guidelines for the Future Treatment of VS," in ANA/NJ Newsletter (Oct 2018).

[5] See S.Selesnick et al, "The Changing Clinical Presentation of Acoustic Tumors in the MRI Era, *Laryngoscope* (April 1993); and discussion in "Acoustic Neuroma Sizes and Symptoms," ANA/NJ Newsletter, online (Sept 2005, Jan 2006).

[6] See for example "Choosing Between Surgery and Wait-and-Watch," ANA/NJ Newsletter (Sept 2004), a review of T.Tos et al, "Long-term Socio-economic Impact of VS for Patients under Observation and after Surgery," *Jour Laryngology & Otology*, Vol 117 (Dec 2003).

[7] *The Washington Post* (Feb 2016), reprinted in the Spring 2016 newsletter of the Acoustic Neuroma Association of Canada (www.anac.ca/newsletters). Carol Krucoff is a yoga therapist at Duke Integrative Medicine in Durham, NC. She is the author of several books on yoga.

game' had its moments of anxiety, but the delay in treatment also meant she was able to benefit from a further decade of important advances in radiation technology.

Carol's tumor grew at the rate of 1 mm/year. Danish studies have shown that hearing may decline during observation even though periodic MRIs show little or no tumor growth. Much depends on quality of hearing at the time of diagnosis.[8] Of patients with 100% speech discrimination at diagnosis, 69% maintained good hearing after more than 10 years of observation. Of patients with better than 70% speech discrimination, 59% preserved good hearing after about 5 years of observation.

The Mayo Clinic report concludes that tumor size at time of diagnosis has decreased over time and the increased use of radiation for VS in the Unites States has reached an apparent plateau. "Instead, in recent years an increasing number of patients have been allocated to primary observation. Overall, microsurgery remains the most common treatment modality used in the Unites States, but the slow decline seen in past decades has continued."

My Acoustic Neuroma Story

by Kathy Cecere*

My story began in 1993 while at a pediatric ENT appointment with my daughter. I mentioned I'd had mild ringing in my left ear for a couple of years, and the doctor tested me. A very slight hearing loss was detected and he advised yearly exams. For some reason, I kept that report but didn't have more hearing tests. I had young children, was working, and I was "BUSY".

For the next 15 years the "ringing" in my ear gradually increased with strange musical noises, buzzing, a TV or radio left on. I still didn't notice a hearing loss, but noisy settings like weddings, large restaurants, business meetings, were pretty unbearable. Sometimes I felt a "floating" sensation. I described it to my doctors at any routine exams. I was offered tranquilizers, antidepressants, etc., which I declined. I still didn't consult an ENT. I didn't feel "bad", and I was "BUSY" with children and working.

In December 2008, the tinnitus went crazy and I started bumping into doorways and walls. I saw my family doctor 3 times in 2 weeks. She sent me to a neurologist for an MRI. Just before Christmas I was told I had an Acoustic Neuroma measuring approximately 9x4x5mm. The neurologist recommended an ENT. This time I paid attention. I also found ANA/NJ online. I sent an email, and Wilma Ruskin called me immediately. I'm thankful for that call! It led me to the moral support of ANA/NJ meetings. I relaxed enough to enjoy a busy holiday with lots of guests, and when January 2009 arrived I started researching specialists. I made an appointment with the ENT, who was excellent and offered very good advice. I also found an AN specialist and was on Wait/Watch for 2 years, having MRI's every 6 months.

Then tumor growth began and having treatment was recommended. I felt it best to get more opinions. I consulted with several excellent doctors, in-person, online, even out-of-network (very costly!). ALL said that I should treat; I was a good candidate for surgery OR radiation, but the choice was mine. It was an agonizing choice for me. I dove into information. I finally decided surgery was best for me; radiation would be there if I needed further treatment. I found my comfort zone with Drs. Selesnick and Gutin at Weill-Cornell and Sloan-Kettering in New York City. I had retrosigmoid surgery at Sloan-Kettering in July 2010, when my AN was approximately 1.5cm, touching my brainstem. During surgery my facial

[8] S.Stangerup et al, "Long-term Hearing Preservation in Vestibular Schwannoma," *Otol Neurotol*, Vol 31 (Feb 2010).

nerve was found badly involved with the AN, so a partial resection was done (as planned beforehand, just-in-case), leaving a bit of the AN. After surgery my balance was good; no facial nerve issues or headaches, still some tinnitus. I had reduced hearing in the affected ear from about 80% word recognition before to about 30% after. I had some vestibular therapy as recommended and still do simple balance exercises. I went back to work after 8 weeks.

By 2015 the residual tumor began to enlarge, and I had to make a decision for radiation treatment, but by what method, single or fractionated? I chose single session treatment Gamma Knife at NYU with Dr. Kondziolka (Feb 2015). It was not difficult, and I felt no side effects. The aftermath of the GK has been as expected. After some initial swelling the tumor size decreased and has remained stable. The hearing in my left ear has gradually faded to almost nothing. Still some tinnitus, noisy settings remain difficult, but life is good. My next MRI will be two years from now. I'm very grateful to the wonderful doctors who treated me, and to those I consulted. We're busy with life, family and 4 grandsons. When I think of that hearing test in 1993, I guess I've had a long Wait/Watch journey.

*Kathy is listed in the *ANA/NJ Directory* (June 2014). She is a member of our executive board.

Have You Taken a Look at PubMed.gov?

PubMed.gov has been called the "true liberator of medical knowledge in the National Library of Medicine."[9] Virtually all published medical articles from the thousands of professionally recognized and peer-reviewed journals are archived on this website in summary form. PubMed comes with a powerful search engine that will quickly identify by topic virtually all research reports. The National Library of Medicine has zealously pursued the goal of making medical information free, open and easily tapped.

National Library of Medicine
Bethesda, Maryland

Articles in our newsletter are often footnoted to encourage you to take a look on your own at the important research reports about acoustic neuroma that are available to you in the medical journals. Simply go online to www.pubmed.gov and use the search engine to call up the abstracts of the reports we have cited. PubMed will also direct your attention to related reports. Although for some reports you will find a link to a free full-text copy, mostly PubMed provides only directions for ordering copies from various reprint companies (at much too high a cost, we think). Better would be to ask the Interlibrary Loan Service at your local library to order a copy of the report you wish to read in full. There may or may not be a small charge.

[9] See "PubMed! The True Liberator of Medical Knowledge," ANA/NJ Newsletter (Sept 2007).

GIFTS & DONATIONS to ANA/NJ

January 1, 2017 – December 31, 2018

The Executive Board of ANA/NJ gratefully acknowledges those who have contributed to ANA/NJ in support of its mission to provide information, encouragement and support to acoustic neuroma patients and their families.

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In Memory of Betty L. Springfield
- Harry E. Springfield, Jr.

In Memory of Amy Grossman
- Princeton Medical Group
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Spring Meeting

"Caring and Sharing"
Open Meeting for Acoustic Neuroma Patients, Family & Friends

Sunday, March 31, 2019
1 – 4 pm
Summit Medical Group
Lawrence Pavilion, One Diamond Hill Road
Berkeley Heights, NJ

Group Discussion Q&A Refreshments Social Time

(RSVP to ananjinc@aol.com)

_____Directions_____

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

• From **Route 78 East**, take **Exit 43**, **Berkeley Hts/Watchung**. Follow the long exit road to the light at Valley Rd and turn left onto **Valley Rd**. Go to the first light and turn left onto **Diamond Hill Rd**. Follow Diamond Hilll Rd to the light at **Mountain Ave.** Go left on Mountain Ave for a very short distance to the entrance for Summit Medical Group on your left. You will see Lawrence Pavilion and parking straight ahead as you enter. Bear to the right for parking and look for the **ANA/NJ Meeting** sign for the side entrance to the Pavilion.

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