

## ANA/NJ Virtual/Zoom Meeting February 28, 2021

Seventeen ANers including five board members attended our first trial “Zoom” meeting held Sunday afternoon, February 28, 2021. This turned out to be a very interesting and



rewarding new way to share information and personal experiences about acoustic neuroma. The atmosphere was relaxed and friendly. Many thanks go to Dave Belonger for arranging and moderating the session. Toward the close of the session there was agreement with Wilma Ruskin’s suggestion that we might try having a “virtual” meeting with a speaker – perhaps someone to present for hearing devices, or maybe tinnitus.

The meeting was an open discussion of a wide range of experiences with acoustic neuroma, including: (1) users of Phonak’s CROS hearing aids shared their experiences with this system for transmitting sound from the deaf side to the normal ear (CROS); BiCROS if there is some hearing loss in the normal ear; (2) two long-term Wait-and-Watch patients (17 years and 22 years) discussed MRI check-up intervals. It was noted that, for the multiple check-up scans needed for Wait-and-Watch, the possibility of having non-contrast MRIs could be discussed with your doctor. (See the article

on “Wait-and-Scan Management” in the October 2019 issue of the Newsletter); (3) Gamma Knife radiosurgery (single-session) and CyberKnife radiotherapy (three sessions) were compared briefly; (4) there was discussion about types and ways to deal with tinnitus, including “Musical Ear Syndrome”; (5) coping with dry eye; (6) balance problems; (7) a case of cerebrospinal fluid leak (CSF).

Many thanks to all attendees for a very informative meeting with lively discussion. Stay tuned for future Zooms.

### MRI Scanning for Older Patients

Researchers at Cambridge University Hospitals, Cambridge, UK, have noted “there is a need for a surveillance protocol to determine if and when we can stop imaging safely [Wait-and-Watch] patients aged 70 years and over.”<sup>1</sup> They looked at the records for 112 observation patients. The median age was 74 years at diagnosis. Twenty-nine percent of VSs displayed growth (6% continued surveillance, 23% received active treatment). “Since no VSs grew after 42 months from diagnosis, our data support an initial magnetic resonance imaging (MRI) at 6 months after diagnosis followed by an annual MRI for 3 years. At this point, consideration could be given to discussing discontinuation or further imaging with patients.”

<sup>1</sup> D. Borsetto et al, “When Should We Stop Scanning Older Patients with VS,” *Jour Neurol Surg B, Skull Base*, Vol. 80(4) (Aug 2019). PubMed abstract.

## ANA/NJ

Acoustic Neuroma Association  
of New Jersey

A Non-Profit Corporation

Website: [www.ananj.org](http://www.ananj.org)

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## Notices!

- “Healthy hearing is not just about the volume of sound, but about the broader ability to communicate. The most frequent complaint from patients with hearing loss is their ability to understand speech, which is due to a lack of clarity and loss of intelligibility where patients can’t recognize words and follow conversations.” Frequency Therapeutics, a biotech company headquartered in Woburn, Mass., has announced success in clinical trials for enhancing speech recognition performance using Intratympanic FX-322. Search [www.pubmed.gov](http://www.pubmed.gov) for W. J. McLean et al, “Improved Speech Intelligibility in Subjects with Stable Sensorineural Hearing Loss following Intratympanic Dosing of FX-322 in a Phase 1b Study,” *Otology and Neurotology* (Feb 22, 2021).

- The Department of Otolaryngology at Loyola University Medical Center, Maywood, Illinois, surveyed 166 patients who underwent acoustic neuroma surgery, 2009-2014. “Of the 53 patients who completed the survey, 17% reported their tinnitus resolved; 9% reported improvement; 23% reported no change; 43% reported their tinnitus worsened; and 8% were unsure.” See J.Bell et al, “The Persistence of Tinnitus after Acoustic Neuroma Surgery,” *Otolaryngol Head Neck Surg*, Vol. 155 (Aug 2016).

- The latest Gamma Knife model, ICON, allows for frame-based or mask-based radiosurgery. Either single or multiple session treatment can be delivered. UCSF in California reports using the stereotactic head frame for the precise positioning required for single session treatments; multiple session treatments use a custom-molded plastic mask plus CT scanner and infrared camera for aiding positioning. Mayo Clinic has reported (2021) that early clinical experience suggests that mask-based GK is a safe alternative: “Patients with large target volumes where fractionation is preferred, or with small target volumes in non-eloquent areas, can be considered for this approach.” Rutgers University has reported (2018) concern over motion variations: “The variability in motion error associated with mask fixation must be taken into account when planning for small lesions or lesions near critical structures.” Columbia University has noted (2020): “We look forward to studies with longer follow-up to provide valuable data on clinical outcomes.” (See A.Bush et al, “Mask-based Immobilization in GK Stereotactic Radiosurgery,” *Journal Clin Neurosci*, vol 83 (Jan 2021), PubMed abstract).

## My Story: A Postscript

by Phyllis Schreiber

Symptoms of an acoustic neuroma (a sensation of fullness in the right ear, some annoying dizziness) began for me in 1989, but it wasn't until 1998 that I had my first MRI. That's when my 1 cm tumor got diagnosed. I've been Wait-and-Watch since then for 23 years, or even 32 years if you date back to first symptoms. In 2001 I was interviewed for the ANA/NJ Newsletter by Kristin Ingersoll, and that great memory is still available to read on the website. For this brief postscript, I'd like to add a few updates and some more recent reflections about my experience.



I think the initial delay was because my ENT could find nothing seriously wrong based on the office tests he performed; MRI was only just becoming the first line of diagnosis; and my dizziness gradually subsided. But I continued with annual hearing tests, and when these worsened I finally agreed to go ahead with the MRI. The acoustic neuroma (vestibular schwannoma) was revealed. The ENT recommended surgery for treatment. Surgery even for small tumors was routine at the time. However, I was lucky enough to arrange an appointment with the head of neurosurgery at a top hospital in New York City. He told me to Wait-and-Watch to see if the tumor would grow. Even if the tumor doubled in size to as much as 2 cm, he could still do a successful surgery with hearing preservation. And I should not even consider having radiation treatment.

So in 1998 I became a Wait-and-Watch patient having periodic MRIs at two-year intervals. I think now that I chose this management because if I did need treatment, in future, by that time there would be new and less intrusive methods available. Or is this a more recent optimism? One thing no one explained early on is that hearing would deteriorate regardless of type of treatment: observation, radiation or surgery. I've lost all hearing in my affected ear, and my "good" ear isn't all it ought to be either. I wear a standard hearing aid in the "good" ear and use assistive hearing devices. It's interesting that my recollection now is that only after my decision for Wait-and-Watch did I discover the wealth of information and support provided by ANA and ANA/NJ.

My tumor has decreased in size! My last MRI scan, which I reported for the ANA/NJ *Directory* (March 2020) showed a decrease in size from 1 cm to 7 mm. I have been scheduling MRIs regularly at two-year intervals, but am considering discontinuing this observation routine. It bothers me that two times I have had severe bangs to my head, which my doctors have said could make the tumor grow. But I've waited six months before testing again and each time the tumor size has remained the same. Perhaps I've read too much about the unpredictability of acoustic neuromas?

All things considered, I feel blessed with my decision to Wait-and-Watch. I've always attended ANA/NJ meetings, finding all the present-day information so helpful to me and others.

## Facial Functioning and Treatment

Data in ANAUSA's "Patient Registry" is currently being reported in installments in the national association's newsletter, *Notes*. The December 2020 issue looks at patient-provided data for facial functioning at diagnosis and need for postoperative facial treatments. The report shows 85% of respondents (n=748) indicated normal functioning in all areas at the time they were diagnosed with AN. About 11% (n=95) indicated mild facial movement weakness. And less than 1% (n=3) cited severe dysfunction with minimal facial movement, including incomplete eye closure, no forehead motion, and slight mouth movement. For facial nerve treatment following diagnosis, 87% of respondents (n=766) reported having had no surgery or therapy; 9% (n=83) received some type of surgery or therapy; and 4% (n=43) had some other type of treatment.

The report states: "While the number of patients reporting facial nerve problems post-treatment is relatively small, the effects, both physically and socially, can be significant. In recent years, surgical practice and procedures have increasingly focused on a more conservative approach to removing AN tumors, in order to preserve nerve function. Future research into the longer term effects of this more conservative approach will provide a better understanding of the resulting patient satisfaction and rehabilitation."

It's comforting to know that problems with facial functioning for VS patients are much less these days compared to 30-40 years ago. And today there is an abundance of helpful information available for new patients who do have facial issues. Perhaps a good place to begin is with the ANA/NJ *Directory*, which lists patients who invite questions about their experiences with postoperative facial issues. You can phone or email patients. Contact Jane Huck if you need the latest copy of the *Directory* (March 2020).

Another good starter is ANAUSA's Patient Information Booklet, "Facial Nerve and Acoustic Neuroma: Possible Damage and Rehabilitation" (December, 2017), 10 pages, with illustrations and information for surgical and non-surgical rehab, muscle transfer, eye reanimation, botox therapy and much more. For members, ANAUSA also provides access to a Webinar Library. Two most recent presentations are: J. Markey & G. Nina Lu (NYU Langone), "Facial Paralysis Related to Acoustic Neuroma" (2/11/2021); and Dr. Michael Klebuc (Weill Cornell), "The Surgical Treatment of Facial Weakness" (11/24/2020). For visuals of surgical procedures used to treat facial and eye problems, see the earlier webinar (10/18/2016) by Drs. J. Walrath and N. Jowell (Mass Eye & Ear), "Treatment Options for Facial and Eye issues Affecting Post-Surgical Acoustic Neuroma Patients."

The Webinar Library also offers "A Conversation with Jackie Diels."



Jackie (OT) is a leading authority on facial neuromuscular retraining. She is the editor of the Patient Info Booklet cited above and served on the medical advisory board of the Acoustic Neuroma Association during 2002-2017. She currently serves on the medical advisory board of the Facial Paralysis and Bell's Palsy Foundation (Beverly Hills, CA). On the Foundation's website, you can view her webinar: "Neuromuscular Retraining for Facial Paralysis and Synkinesis" (3/15/2019). This is an excellent introduction to facial functioning and non-surgical reanimation therapies. (See also her website: [www.facialretraining.com](http://www.facialretraining.com)).

## Surgery for Small Tumors?

Should surgery be the primary treatment for small (<1.5 cm) intracanalicular tumors? This long-standing question was left unresolved in the “Guidelines on the Treatment of Vestibular Schwannomas” compiled by the Congress of Neurological Surgeons (CNS) (*Neurosurgery*, 2018).<sup>2</sup> The CNS review of the medical literature focused on pertinent studies for the period 1991-2011. The researchers concluded: “While little controversy accompanies the management of large VSs that abut or compress the brainstem, the appropriateness of surgery for intracanalicular VSs continues to inspire debate. Excellent rates of resection, FN [facial nerve] preservation function results, and hearing preservation have been reported after surgery for IAC [in the auditory canal] VSs. However, there are insufficient data to support a firm recommendation that surgery be a primary treatment for this subclass of VS. A comparison study between surgery, observation, and SRS [stereotactic radiosurgery] for IAC VSs may provide better evidence to support one treatment over the other.”

Are you in the process of deciding between treatment options for your small VS? It’s helpful for this purpose to read reports by physicians comparing clinical outcomes for each of the options. Here are some medical journal reports you can consult at [www.pubmed.gov](http://www.pubmed.gov).

- A.Anaizi, M.Pensak et al, “Small Vestibular Schwannomas: Does Surgery Remain a Viable Treatment Option?” *Journal of Neurological*

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<sup>2</sup>[www.cns.org/guidelines](http://www.cns.org/guidelines). See Part 8, Surgical Resection for the Treatment of Patients with VS, Question 4. For more about the Guidelines, see the Newsletters for Oct 2018 & Oct 2019.

*Surgery*, Vol. 77(3) (June 2016), pp.212-18. University of Cincinnati College of Medicine. Free full text copy.

- J.Zou & T.Hirvonen, “Wait and Scan Management of Patients with Vestibular Schwannoma and the Relevance of Non-Contrast MRI in the Follow-up,” *Journal of Otology*, Vol. 12 August 2017), pp.174-84. Changhai Hospital, Shanghai and Helsinki University Hospital, Finland. Free full text copy.

- O.Persson et al, “Stereotactic Radiosurgery vs. Fractionated Radiotherapy for Tumor Control in Vestibular Schwannoma Patients: A Systematic Review,” *Acta Neurochir (Wien)*, Vol.159(6) (June 2017), pp.1013-21. Karolinska University Hospital, Stockholm, Sweden. Free full text copy

- C.Barnes et al, “Fractionated Proton Beam Therapy for Acoustic Neuromas: Tumor Control and Hearing Preservation,” *Internat Jour Part Therapy*, Vol.4(4) (Spring 2018), pp.28-36. Loma Linda University Medical Center, Loma Linda, CA. Free full text copy.

- M.Carlson et al, “Long-term Quality of Life in Patients with VS: An International Multicenter Study Comparing Microsurgery, Radiosurgery, Observation & Nontumor Controls,” *Journal of Neurosurgery*, Vol.122(4) (April 2015), pp.833-42. Mayo Clinic. Abstract.

- M.Carlson et al, “The Changing Landscape of VS Management in the US – A Shift Toward Conservatism,” *Otolaryngology – Head & Neck*, Vol. 153(3) (2015), pp.440-46. Mayo Clinic.

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## My Hearing Journey

by Alix Garzero\*

It started out as a great year. I was 29, lived in San Francisco, and my post-college job provided health insurance. I scheduled a hearing test, which I needed because I didn't hear well on the left side. That hearing test led to the MRI that showed an acoustic neuroma the size of a large egg! I didn't have time to consider treatment options because my diagnosis and emergency surgery were less than a week apart. My MRI was Thursday; and at Friday's diagnosis the ENT advised that I was past "Wait and Watch" and needed brain surgery. Just a few days later (Monday) I had a crushing headache and couldn't feel my feet or legs. My sister called the ENT who had diagnosed my AN, and he told her to take me to the Emergency Room at the University of California/San Francisco, where Drs. Robert Jackler and Laurence Pitts were renowned acoustic neuroma specialists. I was admitted and met Dr. Pitts, who explained that my AN (3.5 - 4.7 cm) was the second-largest tumor he had ever seen.

Surgery was my only option, so I listened to all the worst-case scenarios from Dr. Pitts and his caring residents and waited for Wednesday. After the 13.5-hour translabyrinthine surgery (not unusual for a large tumor), it suddenly seemed that I had \*every\* post-surgical problem. Everything hurt. I had "the spins" and double-vision, and my left eye didn't tear or close -- in fact the left side of my face was paralyzed. I was sensitive to light and sound. I didn't process how profound my single-sided hearing loss was. I took ibuprofen for pain, used Lacrilube for my eye, and walked to regain my balance, but I didn't address my single-sided hearing loss. The surgery was successful and I thought I was coping with hearing OK, but the truth was I was missing a lot of what people were saying.

After I moved to New Jersey, I was still ignoring my hearing problem when I had a routine appointment with a Summit Health neurologist, Calvin Natonzon. Dr. Natonzon suggested I consider hearing aids. He told me that the part of my brain associated with hearing had atrophied more than the rest of my brain because I was only hearing on one side. Some brain atrophy is normal, but I was too young for that much hearing loss. So I consulted with Summit Health audiologist Kayla Holstad. Dr. Holstad is wonderful and made sure that my new Phonak CROS hearing aids worked optimally and were comfortable. I recommend both of these medical professionals highly.

The benefits of hearing outweigh any slight discomfort -- I've gotten used to the way my CROS behind-the-ear hearing aids feel. They were my best option back then and they've held up well. My left ear transmitter sends sound to the right hearing aid via Bluetooth. The right hearing aid amplifies sound so that I can hear more of what's going on around me. The CROS is customizable, so if you have right-sided hearing loss the transmitter will be on the right.

Now I hear more of what people say, even in crowded situations, and that's important. Crucially, I hear soft-spoken people better. I also enjoy music again, even if the sound quality isn't the same. Besides Phonak, there are other manufacturers, like Signia and Starkey. I suggest consulting an audiologist and asking questions. A good audiologist will listen to what you need and provide info and sound advice 😊. Also, hearing aids aren't the only technology available for those of us with hearing deficits. Dr. Holstad advised that some of us could qualify for a no-cost Internet-based CapTel (captioned telephone).

Phonak CROS aids were top of the line when I purchased them, but this technology has exploded and my next aids will surely be even better. I encourage anyone with hearing loss, especially single-sided deafness, to engage in the world around you and consider hearing aids to improve your health, well-being, career, and social life. Hearing aids are an investment in yourself.

\*Alix is listed in the ANA/NJ Directory (March 2020). She invites questions and discussion.

# ANA/NJ Virtual Support Meeting

Sunday October 24, 2021

1:00 to 3:00 p.m. EST

TOPIC:

## *“Options for Better Hearing”*

A Discussion of Hearing Devices, with Introduction and Q&A by  
Dr. Jed A. Kwartler

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Jed A. Kwartler, MD, is Director of Summit Health Otolaryngology/Neurotology and Clinical Associate Professor of Otolaryngology at the University of Medicine and Dentistry of NJ in Newark. He has taught courses on acoustic neuroma surgery, age-related hearing loss, and hearing rehabilitation. He serves on international panels that evaluate the latest implantable and semi-implantable hearing devices.

Currently the Acoustic Neuroma Association of New Jersey (ANA/NJ) is limiting its sharing and educational meetings to virtual ‘Zoom’ opportunities. Please mark your calendars and plan to join the October 24, 2021, virtual support meeting.

**Space is limited. Sign up soon.**

You do not need to be a resident of New Jersey or a particular area in New Jersey or a member of ANA/NJ to participate, but **you do need to register** [registration information below]. Family members, caregivers, friends, and interested persons are welcome to attend as well. Bring your questions and join peers for this interactive opportunity.

**In order to receive a confirmation email with detailed instructions** to join our Zoom meeting, send an email to Dave Belonger at [dbelonger@verizon.net](mailto:dbelonger@verizon.net) requesting attendance at the October 24<sup>th</sup> meeting.

*We look forward to welcoming you!*



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