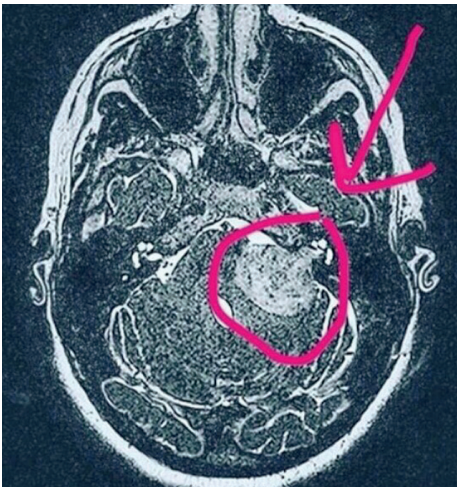


NOTES



THROUGH TRAUMA COMES STRENGTH

by Meagan Doumont
Maple Ridge, British Columbia

2016 was supposed to be my year. I graduated nursing school, was hired in the neonatal intensive care unit and was one of the lucky ones who was actually paid to do specialty training. Everything was falling into place! Or so I thought.

After an ongoing investigation of single-sided hearing loss, balance issues, severe headaches, exhaustion and facial numbness, I finally had to face what my body was trying to tell me—I had a large brain tumor growing in the base of my skull. At 30 years old, in what was supposed to be the peak of my life, I was told news that would ultimately change my life forever.

Voyages continued on page 15

MEDICAL REPORT: DIZZINESS AND VESTIBULAR SCHWANNOMA

Jeffrey D. Sharon, MD, Assistant Professor, Director of Balance and Falls Center, Division of Otolaryngology, Neurotology, and Skull Base Surgery, Department of Otolaryngology - Head and Neck Surgery, University of California, San Francisco



One of the interesting features of acoustic neuroma/vestibular schwannoma (VS), is that the most common initial symptom is hearing loss. Despite that, vertigo and dizziness are common with VS and are some of the most important symptoms - along with headache - that seem to determine someone's quality of life (Carlson 2015). As the 8th cranial nerve, the audio-vestibular nerve, exits the brain and reaches the organs of hearing and balance in the inner ear, it splits to become three nerves: the cochlear (hearing) nerve, and an upper (superior) and lower (inferior) vestibular nerve. The hearing and balance nerves lie close to each other, explaining why both show dysfunction with VS.

An overview of how the vestibular system works is useful in understanding dizziness and vertigo, i.e., how it normally functions, what happens when it stops functioning, and how we treat vestibular dysfunction at different stages of tumor treatment.

So, what is the vestibular system? It is like one of our senses (similar to sight or hearing) and enables us to sense head movement and gravity. This is critical for several reasons. First, picture what would happen if you took your phone's camera, and ran down a corridor with the phone in front of you, recording what you saw. The recording would probably make it look like the world was bouncing and shaking. If you were running quickly enough, the world would look blurry as well. Now compare that to your view if you ran down the corridor. When you run, the world seems to be steady and in focus. Our eyes are actually quite similar to a video camera, capturing details about the visual world. The vestibular system is our image stabilization system, similar to a gimbal for a camera. So, if we want to keep vision steady as we run, each time the head moves up, the eyes should move down, and vice versa. That ensures that there is no net movement of the eyes. If the eyes do jiggle around too much when we move, then the image slips off the back part of the eye that "senses" visual objects, causing them to appear blurry. Because the vestibular system is able to sense our own head movements, it can keep our vision steady as we move by controlling eye movements, and compensating each time our head turns, bobs or shakes.

Medical Report continued on page 6

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My Experience as a Volunteer Board Director



by Marla Bronstein

About ten years ago I was diagnosed with an acoustic neuroma. Against the advice of one of the surgeons I consulted, I Googled vestibular schwannoma. Fortunately, one of the first hits was to the ANA website. This was where I learned that I was not alone in suffering decreased hearing, balance issues and tinnitus. The ANA's Discussion Forum and local support group meetings were my touchstones for the months leading to surgery. I continued going to local meetings well after my treatment to support others who were diagnosed and to stay connected to the people who share this life-changing event.

A few years later, I attended the 2013 ANA Symposium in Los Angeles, where I was empowered by the number of people in attendance who were in various stages of their journey. Some had undergone treatment more than 30 years before I was diagnosed. Others had received the results of their MRI that very week.

One of the discussion panels I attended consisted of a few board members. These were people who, like me, had found support and encouragement from the ANA. They spoke of giving back to the ANA by being active in the AN community. Jeff Barr, then president of the board, invited those interested in supporting the organization in a powerful way to apply to serve on the board. He didn't have to ask twice— I joined the board in April 2014.

Board directors attend five meetings per year (two in-person). During my time on the board, I have been to a number of the patient education events hosted at treating hospitals across the country. I have attended and led local peer groups. I am available to talk with those who are newly diagnosed. One of my favorite things is making connections. This year, I look forward to moderating a virtual support group consisting of recently diagnosed musicians who are concerned about hearing loss.

Although I don't need to be a member of the board to do these things, my involvement has provided a more extensive overview of the AN community and the organization that I serve; it has enhanced my understanding of areas of need.

Until researchers find a way to prevent acoustic neuromas from forming, I want the ANA to be around. Being on the board gives me an opportunity to ensure that the ANA remains in existence.

I recently realized that I consistently forget to invite people to join me on the board. Consider this your invitation! Won't you join me? There is room on the board for you and you will not regret it!



The Acoustic Neuroma Association is seeking exceptional volunteers to serve on our National Board of Directors, specifically with legal, financial or project management skills. Board members are dedicated to the mission, vision and values of the organization and work with a diverse team of staff and volunteers to provide oversight and execute the strategic plan. For more information, contact **Melanie Hutchins, volunteers@ANUSA.org**.

ANA PATIENT REGISTRY RESULTS

Radiosurgery Treatment

Installment Four of ANA Patient Registry Data Reporting

We hope you will continue to provide valuable data by participating and updating your information each year. Go to <https://connect.invitae.com/org/ana> and login. Your most recent date of participation in the ANA Patient Registry will be listed. If it has been over one year, please click the 'update survey' link and provide your updates.

While the most frequent treatment for acoustic neuroma has been microsurgery, a relatively small percentage of participants also needed radiological treatment as a follow-up procedure. There is a growing interest in and use of various radiological interventions as primary as well as secondary (following microsurgery) treatment. The collection of data below reports on the use of different types of radiosurgery as well as the duration and number of treatments received.

Radiosurgery

There were 57 participants who indicated they had received radiosurgery or radiotherapy. Most had received Gamma Knife (68%), followed by CyberKnife (19%), and linear accelerator (11%). The proton accelerator (2%) was experienced by the fewest participants, likely due to the relatively recent availability of this form of radiosurgery.

Was acoustic neuroma treated with radiosurgery or radiotherapy?	Frequency	Percent
Gamma Knife (Leksell) Gamma Knife-Elekta Corporation	39	68
CyberKnife	11	19
Linear accelerator (LINAC)	6	11
Proton accelerator (proton beam)	1	2

Of the 57 participants who indicated they had received radiosurgery or radiotherapy, 54 reported the specific number of sessions. By far the most frequently reported radiosurgery was a single session (74%). The remaining 14 participants (26%) reported treatment lengths ranging from less than 1 week to more than 5 weeks in duration. Three participants were unable to indicate the duration of their radiation treatment program.

What was the duration of the radiation treatment, from beginning to end?	Frequency	Percent
Single session	40	74
Less than 1 week	5	9
1-2 weeks	5	9
2-3 weeks	1	2
More than 5 weeks	3	6

The number of times a patient receives a radiation treatment may range from a single treatment to multiple treatments with varying amounts of radiation exposure. Of the 57 participants who received radiosurgery or radiotherapy, nearly one-half had received a single dose ($n = 28$) while 26% received a range from fewer than 5 up to 30 individual treatment exposures. Slightly more than 25% of participants were unable to provide the number of radiation treatment exposures.

Registry continued on page 4

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How many total treatments (fractions) did the patient receive?	Frequency	Percent
Single dose	28	49
Fewer than 5	6	11
5-10	5	9
10-15	1	2
26-30	2	4

Both Microsurgery and Radiotherapy

A frequent question is ‘What about patients who had to have both surgery and radiation?’ The registry provides us with a small amount of information on that issue. Of the patients who received both microsurgery and radiotherapy, there were 48 participants who indicated they received both types of treatment. In particular, 18 participants indicated they received translabyrinthine microsurgery and Gamma Knife radiosurgery (38%) and 12 participants reporting retrosigmoid/sub-occipital microsurgery and Gamma Knife radiosurgery (25%). We don’t know the exact reasons for the choices of either the microsurgery or the radiation method but it is the case that the Gamma Knife treatment has been available longer than the other three methods of radiation.

Was the acoustic neuroma treated with both surgery and radiation?

		Middle Fossa approach	Retrosigmoid/sub-occipital approach	Translabyrinthine approach	Total
Gamma Knife	Count	3	12	18	33
	% of Total	6%	25%	38%	69%
CyberKnife	Count	0	2	7	9
	% of Total	0%	4%	15%	19%
Linear accelerator	Count	1	1	3	5
	% of Total	2%	2%	6%	10%
Proton accelerator	Count	0	0	1	1
	% of Total	0%	0%	2%	2%
Total	Count	4	15	29	48
	% of Total	8%	31%	60%	100%

While the registry respondents do provide us with some specific information about their experiences with radiosurgery or radiotherapy, we were not able to determine the amount of the radiation dosage. The magnitude of the dosage is certainly related to the specific characteristics of the tumor (e.g., size, location, etc.) as well as the type of radiological method employed in the treatment.

In the next installment we’ll look at some of the post-treatment symptoms and side-effects reported by the Registry respondents.

ANA Patient Education Event

REGISTER NOW

www.ANAUSA.org/UCSD

Hosted by the University of California San Diego

Friday, June 19

6:30 - 8:30 p.m.

Saturday, June 20

8:00 a.m. - 4:00 p.m.

UC San Diego, San Diego, CA

Presentations for patients and care partners at all stages of the AN journey. There will also be time for Q&A and networking.

This event is free but registration is required.

**Questions or assistance
Stephanie Rommer
770-205-8211
events@ANAUSA.org**



AN RESEARCH UPDATE

Mayo Clinic Quality of Life (QoL) Survey - Year 5 Update

by Matthew L. Carlson, MD and Michael J. Link, MD
Mayo Clinic, Rochester, MN



We are immensely grateful to everyone who completed the Mayo Clinic quality of life survey questionnaires - thank you! To date, we've received completed surveys from 1,362 people, which is outstanding. Your responses to these surveys provide very valuable information that will ultimately help inform future patients about what to expect after being diagnosed with a vestibular schwannoma and about treatment options. We wish to provide you with a brief progress report on our quality of life study by sharing the results from two talks that will be presented at upcoming



national medical society meetings.

The first talk focuses on how quality of life changes after treatment. This study included responses from every person who completed a baseline survey, before receiving any treatment, and at least one additional survey after the treatment was complete. With this information, we can determine how much each person's quality of life changed as a result of treatment. In this study, we analyzed the results of 370 people; 80 who received radiation, 172 who had surgery, and 118 who chose to observe their tumors without treatment. The results of this study showed that the change in quality of life is not significantly different among the different treatment options for most categories. Interestingly, the only category that showed an advantage with a particular treatment was a greater improvement in anxiety for people who had surgery.

The second study evaluates whether one particular treatment has the potential to make certain symptoms better or worse, compared to another treatment. Most of the research about vestibular schwannoma pertains to hearing loss and facial nerve paralysis. This study is unique because it investigates changes in tinnitus, headache, dizziness and imbalance. Specifically, we sought to answer the question, if a person has a very

"The results of these two studies confirm that in most cases there is not one single best treatment. It is important to keep an open mind when considering different treatment options and it is generally advisable to seek counseling from several medical centers that have extensive experience with both radiation and surgery."

severe symptom such as tinnitus at time of diagnosis, is one treatment better than another for alleviating this particular symptom? As it turns out, after about two years following treatment there was no difference in how much each symptom changed, regardless of treatment. In other words, this study suggests that people should not choose one specific treatment option believing that it has a greater chance of improving dizziness, tinnitus or headache.

Taken together, the results of these two studies confirm that in most cases, there is not one single best treatment. It is important to keep an open mind when considering different treatment options and it is generally advisable to seek counseling from several medical centers that have extensive experience with both radiation and surgery. You should think about what your personal priorities are and discuss them with your provider in order to select the treatment that best meets your individual goals.

We once again wish to thank those who contributed to this research study by completing the Mayo Clinic Vestibular Schwannoma Quality of Life Survey questionnaires.

To enroll, please visit
www.ANAUSA.org/mayo-clinic-study
or email
RSTacousticneuromastudy@mayo.edu

Another function of the vestibular system is to maintain our balance. By sensing gravity and head movements, the vestibular system can help adjust different muscles to keep us from falling. Other systems, such as vision, the sensation of the ground under our feet, and the position of our arms and legs, also help with balance. The vestibular system is critical in preventing falls, especially if those other systems are compromised, as would be the case if one were to walk on an uneven surface in the dark.

With hearing, people typically notice when they lose function or can't hear as well on one side. However, the vestibular system has some redundancy and our brains have an ability to compensate. That means that if we slowly lose vestibular function on one side, due to an enlarging VS for example, it may or may not be noticeable. The brain will usually adapt and compensate, relying more on the vestibular system of the healthy side, but when tested, about 75% of VS patients have lost at least some degree of vestibular function on the tumor side (Thomeer 2015). As function is lost, there can be episodes of vertigo, the sensation that the world is spinning. That is because each ear is constantly sending vestibular information to the brain. Whenever we turn our heads to one side, the signal on that side goes up, and the signal on the other side goes down. That means, if I suddenly lose function, my brain will be tricked into thinking I am turning. It will begin to move the eyes to compensate and vertigo will result. In addition, as vestibular function is lost, quick head turns to the side of lost function (right or left) can result in imbalance or blurry vision. That is because the image stabilizing function of the vestibular system is degraded.

We have already reviewed how VS can cause dizziness by slowly degrading the function of the vestibular nerve. It's also important to know that with very large tumors, blockage of cerebrospinal fluid flow can occur, resulting in hydrocephalus. Hydrocephalus can result in headache, disorientation, and difficulty walking. It is considered a medical emergency,

requiring timely surgery to remove the tumor and relieve the obstruction.

Treatment decisions for VS depend on a host of factors, including tumor size, patient age, medical history, hearing, vestibular status, and the preferences of the patient and physician. Ideally, these decisions are made together as a team. Microsurgical removal of the VS almost inevitably results in removal of any remaining vestibular nerve. This is because the tumor engulfs the nerve as it grows, separating and eroding the individual nerve fibers. As long as balance function works on the other ear, most patients compensate afterwards. Physical therapy is frequently recommended to help with balance recovery, and numerous studies have shown that it is very beneficial, especially in older patients (Vereck 2008, Herdman 1995, Enticott 2005).

For patients with disabling vertigo, studies have shown that microsurgical removal results in resolution of the vertigo in most patients, with improvements in dizziness related to quality of life (Godefroy 2007). The brain's ability to compensate after a vestibular injury does depend on several factors, including good eyesight and a functioning cerebellum. Therefore, if a cerebellar or a brainstem stroke occurs (a surgical complication), this can make vestibular compensation incredibly difficult. Thankfully, this is rare.

There is much less data on the effects of radiation for disabling vertigo. One study pooled data from several observational studies and found that overall, patients thought that their dizziness improved more with surgery than radiation, although there were improvements in both groups (Kim 2019). This seems to make sense, because radiation may not result in complete silence from the vestibular nerve, and the misfiring of a doubly damaged nerve may contribute to symptoms. However, surgery is not the only way to "silence" the vestibular nerve. Aminoglycoside antibiotics are toxic to the inner ear. This "side effect" is usually a bad thing, but in medicine, we can sometimes find a use for an otherwise

poisonous substance. These antibiotics (ex., gentamicin) can be directly injected through the eardrum into the middle ear space, where they will seep into the inner ear and degrade residual vestibular function. This can be quite useful, if someone has ongoing dizziness after radiation for VS, as an alternative to invasive surgery. The main risks involve worsened hearing, and a very slight risk of a hole in the eardrum.

There is an oft repeated tautology in diagnostic medicine: "common things are common". This is important to keep in mind in any discussion of dizziness and VS. In my practice, I frequently find that patients have a cause of dizziness unrelated to their tumor. The two most common causes of dizziness are benign paroxysmal positioning vertigo (BPPV), commonly referred to as "loose crystals in the ear", and vestibular migraine. Both are treatable, and if they can be resolved, give the patient one less factor to consider, leading to an easier treatment decision. It is incredibly important not to assume that the dizziness in VS is related to the tumor, but instead, see a qualified clinician who can properly evaluate this symptom in the larger context. Accurate information is essential for good decision making.

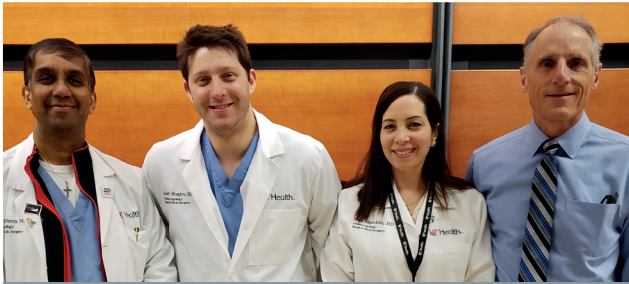
Unfortunately, VS can cause damage to some of the most important nerves in the body, including the balance nerve. The resulting dizziness or vertigo can have a significant impact on quality of life. The good news is that these symptoms are generally treatable, which can make a difference in people's lives.

In no case does the ANA endorse any commercial products, surgeon, medical procedure, medical institution or its staff.

Do not assume that the dizziness in vestibular schwannoma is related to the tumor

Taste Changes after Treatment for Acoustic Neuroma

by Scott Shapiro, MD; Noga Lipschitz, MD; Allen Seiden, MD, FACS; Ravi N. Samy, MD, FACS
University of Cincinnati Medical Center



Skull Base Surgery and Taste Experts from the University of Cincinnati Medical Center. Left to right: Ravi N. Samy, MD; Scott Shapiro, MD; Noga Lipschitz, MD; Allen Seiden, MD

Acoustic neuroma, also known as vestibular schwannoma (VS), is a benign tumor arising from the vestibular (balance) portion of the 8th cranial nerve. Although hearing loss is the most commonly noticed symptom in patients with VS, taste disturbance is also common. Existing research suggests that about 18-40% of pre-treatment patients have symptoms of altered taste,¹⁻³ although it has been much less studied than other symptoms of VS.

Taste disturbance occurs in patients with VS because the vestibular nerves run from their origin in the brainstem in a bony canal toward the balance organs in the ear. This canal also transmits a special branch of the facial nerve called the nervus intermedius which carries taste sensation information, specifically taste from the anterior two thirds of the tongue via the chorda tympani nerve. Damage to this nerve occurs from compression by the tumor, and/or damage during surgery or radiation treatment. Damage can manifest as diminished taste (hypogeusia), or more commonly

an altered taste (dysgeusia), which is often described as a persistent salty or metallic taste. Typically, the taste disturbance occurs only on the front and middle portions of the tongue on the affected side, but in larger tumors the back of the tongue

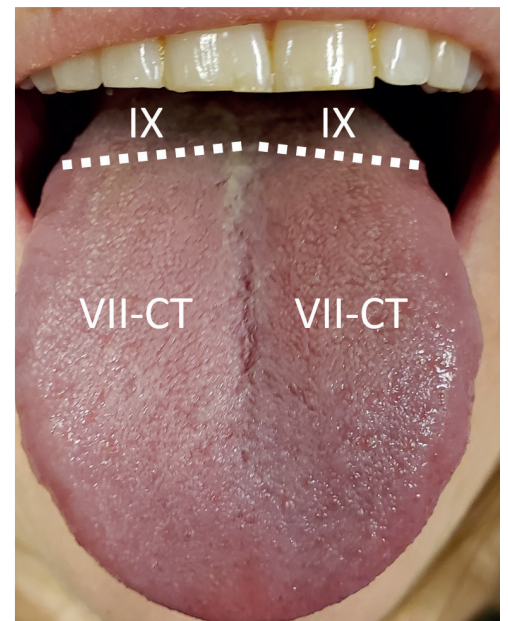
may also be involved.

Taste is a very complex sensory modality, mediated by taste buds on the tongue, palate, and pharynx. These taste buds are innervated by the left and right chorda tympani nerve (via the nervus intermedius), glossopharyngeal nerve, and vagus nerve. The degree of taste disturbance perceived by the patient when only the nervus intermedius of these nerves is impacted is unpredictable. It does not always reflect the size of tumor or the extent of injury to the nerve. In general, about one fourth of patients will develop new taste disturbance after surgery or radiation, though this is usually temporary. Patients with existing taste disturbance who undergo treatment with surgery may see their symptoms improve, stay the same, or rarely, increase in severity.¹⁻⁴

Many patients who sustain injury to the nervus intermedius do not experience a significant taste disturbance. This is likely due to a compensatory relationship with the other cranial nerve territories of taste perception. The same relationship may account

for the frequent dysgeusia that can accompany such injury. Unfortunately, there is no direct treatment that can restore a loss of taste, but it does help to focus on the overall perception of flavor. In addition, there are some occupations in which taste changes have a significant impact (e.g., vintners, chefs, taste consultants, etc.). The perception of flavor is based upon gustatory and olfactory sensation, as well as the texture, temperature, and even appearance of the food. Enhancing other aspects of flavor can serve to make eating more palatable for many of these patients. To treat persistent dysgeusia, some have reported limited success with neuromodulators such as gabapentin or amitriptyline, and the antioxidant alpha lipoic acid.⁵

In no case does the ANA endorse any commercial products, surgeon, medical procedure, medical institution or its staff.



Taste from the anterior two thirds of the tongue is mediated by the ipsilateral chorda tympani nerve via cranial nerve VII, while the posterior third is mediated by the ipsilateral glossopharyngeal nerve, also known as cranial nerve IX.

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Support Groups and Contact Information

We extend our sincere thanks to all the Support Group Leaders and Co-Leaders.

All of the leaders are acoustic neuroma patients or care partners and they understand the acoustic neuroma experience. We are grateful for the incredible amount of support and encouragement they provide to others throughout the different stages of the acoustic neuroma journey.

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Help the ANA reach **more people** in more places.

If there is not a support group in your area, contact **Manager, Volunteer Programs** for information about opportunities near you. volunteers@ANAUSA.org

Highlights from 2019 Support Group Meetings

While providing encouragement is an important component of ANA Support Groups, in-person meetings provide so much more! Guest speakers, panel discussions, informational presentations, product demonstrations, facility tours and collaborative partnerships with other organizations and companies provide exceptional opportunities to learn about a variety of acoustic neuroma topics.

You can see the broad range of topics covered around the country in the list below.



SE New England Group

COLLABORATIVE OPPORTUNITIES

Thank you to the following individuals, organizations and companies that provided beneficial presentations and informational demonstrations to the meeting attendees.

Andrew Leahey, writer and musician

Brian Apprille, professional stand-up comedian and host of Unique Smiles, The Facial Paralysis Podcast

Canine Companions for Independence (CCI)
Lois Fabian and hearing dog, Raegan

Children of Deaf Adults (CODA)
Taci Mathers, ASL Interpreter

Cochlear Americas
Lauren Hall
Deborah Cassidy

Facial Paralysis and Bell's Palsy Foundation
Garden Grove, CA Support Group
San Diego, CA Support Group
Nancy Nolte, Denver, CO Support Group

Hearing and Balance Center of Northern California
Jessie Johnson

Hearing Loss Association of America (HLAA)
Orange County, CA Chapter
Denver, CO Chapter
Rochester, NY Chapter
Fort Worth, TX Chapter

Med-El Corporation
Taylor Sands, Senior Consumer Engagement Manager

NYU Facial Paralysis Support Group
Jeffrey Markey, MD

Ted Bowman, grief and family educator

The Yale Brain Tumor Center
Christa Lizzi, RN

Tucson Adult Loss of Hearing Association (ALOHA)
Karl Hallsten

Alternative Medicine

Potential Benefits of Acupuncture as Treatment for Acoustic Neuroma Related Issues

Balance Issues, Dizziness and Vestibular Therapy

Addressing Balance Challenges Associated with Acoustic Neuroma

Physical Therapy and Dizziness/Balance - What Can Be Achieved?

Returning to Athletic Pursuits After AN Treatment

Caregiving

Group Discussion: How AN Affects Those Closest to Us

Celebrating and Supporting our Caregivers - Special people in your life who are beside you on your AN journey

Case Presentations

Acoustic Neuroma Case Presentations and Panel Discussion

Coping and Cognitive Issues

Cognitive Behavioral Therapy (CBT), Mindfulness Meditation, Relaxation and Coping Skills for Managing Fear and Anxiety Associated with Illness

Responding to Change, Loss and Uncertainty with Resiliency and Hope - An Interactive Presentation

Dealing with the New Normal: How Are You Coping? Transitioning with the Various Changes an Acoustic Neuroma Diagnosis Can Bring

Grieving and Coping with an Acoustic Neuroma Diagnosis

Managing Anxiety after AN Diagnosis

The Cognitive Side Effects of Acoustic Neuroma: An Open Discussion with a Neuropsychologist

Facial Issues and Rehabilitation Options

Facial Reanimation Following Facial Paralysis

Facial Paralysis Issues and Benefits of Facial Neuromuscular Retraining (NMR)

General and Group Discussion

Ask the Doc - Answers to Your AN Questions

Group Discussion: How to Improve Patient Care and Fill in the Gaps

Hearing Issues, Devices and Tinnitus

Hearing Aid Options and Considerations for AN Patients with Single-Sided Deafness (SSD)

Hearing Device Options and New Advances in Technology for Single-Sided Deafness

Hearing Technology for Acoustic Neuroma Patients: How It Works and What Would Be Best for You

Living with Hearing Loss and Single-Sided Deafness (SSD)

Using Helpful Apps and Technologies in Challenging Listening Environments

Maximizing Hearing Rehabilitation

Overview of Managing Hearing Impairments & Single-Sided Deafness (SSD) with Acoustic Neuroma

Tinnitus Management

Updates on Cochlear Implants

Reports from AN Events and Medical Conferences

Recap from the 8th Quadrennial International Conference on Vestibular Schwannoma/Acoustic Neuroma

Report from the ANA Patient Event at Vanderbilt University: Overview of Panel Discussions and Presentations

Treatment Options

Ask the Doc: Acoustic Neuroma Decision Making

Controversies in the Diagnosis and Management of Acoustic Neuroma

Evaluation and Management of Acoustic Neuroma

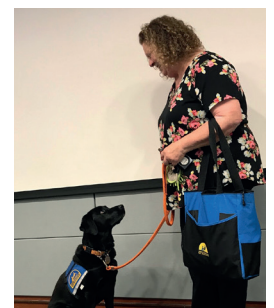
What Now? Modern Strategies for Treating Acoustic Neuroma

Modern Management of Acoustic Neuromas: Emerging Technologies

Treatment Updates for Vestibular Schwannoma

Fractionated Stereotactic Radiotherapy (FSR) for the Management of Acoustic Neuromas

CCI representative
Lois Fabian with hearing dog, Raegan



SPONSOR ARTICLE

A Team Built Around the Patient

Bernard R. Bendok, M.D., chair of Neurosurgery at Mayo Clinic in Phoenix/Scottsdale, Arizona, answers questions about advances in the management of acoustic neuromas.

How has the approach to treating acoustic neuromas changed?

Advanced technology and a new focus on quality of life have greatly improved treatment options for people with acoustic neuromas.

Twenty years ago, the treatment choices — watchful waiting, surgery and radiotherapy — were seen as competing with one another. The recommended approach often depended on whether the recommendation came from a neurosurgeon, a radiation oncologist or an otologist. Now, we try to avoid that competition by having an entire team integrated around the patient.

We've moved to an era of multidisciplinary decision-making and sometimes complementary treatment options. It's very important for a patient to get opinions, not just from one doctor, but from an entire acoustic neuroma team. At Mayo

Clinic, we have a team built around the patient rather than around the doctor.

What technological advances have occurred?

Improved imaging allows us to plan surgeries in ways that better avoid damage to the facial nerve. We have some novel MRI sequences that have improved visualization of the nerves surrounding the acoustic neuroma in many cases.

In addition, we have enhanced intraoperative MRI and intraoperative CT that help us navigate around the nerves during surgery. These advanced imaging modalities can be used for complex cases, including recurrence of an acoustic neuroma.

Other advances in microsurgery techniques have made acoustic neuroma surgeries safer than they were 10 or 20 years ago.

What role can radiation therapy play in treatment?

The radiation therapy known as stereotactic radiosurgery is a very viable option for treating small

tumors. The therapy is safe, it can stop the tumor's growth and sometimes it can shrink the tumor. Radiosurgery is an option that every patient should consider for smaller tumors.

How might treatment approaches be combined, to address the needs of an individual patient?

Surgery can be successfully combined with observation and radiosurgery. For example, if a tumor is too large for radiation therapy, and complete resection poses risks to the facial nerve, we might leave a small piece of tumor next to the nerve. That residual tumor can then be treated with observation or with radiosurgery.

How do quality of life concerns influence treatment approaches?

Most acoustic neuromas aren't immediately life-threatening — that means it's important for us to focus on patients' quality of life. At Mayo Clinic, we use questionnaires to measure quality of life and incorporate that information into our decision-making.

[Mayo continues on page 13](#)

Sponsor Spotlight



Mayo Clinic experts have extensive expertise diagnosing and treating acoustic neuroma and care for about 800 people a year with acoustic neuroma. Mayo Clinic doctors use the latest tools and techniques, including stereotactic radiosurgery and other innovative technologies. For example, Mayo

Clinic neurosurgeons are among the first to use an advanced form of brain tumor imaging called magnetic resonance elastography (MRE), which was invented at Mayo Clinic, with related slip interface imaging. Together, this combination provides a clearer picture of the firmness and degree of attachment of brain tumors to the surrounding healthy tissues to help surgical planning and reduce uncertainty before going into surgery.

With access to state-of-the-art laboratory and clinical facilities, Mayo Clinic researchers are innovators in the care of acoustic neuroma. Current research topics include investigating the genetic causes of acoustic neuroma and its growth and a long-term study of quality of life issues. For more information visit mayoclinic.org/acousticneuroma.

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SPONSOR ARTICLE

Back to Adventure

Ninev looks forward to his adventure vacations. In his early fifties, he enjoys biking, mountain trail hiking and boating. He even learned to scuba dive. Then he started noticing problems with the hearing in his right ear.

Soon after, he consulted his primary care physician, who attributed his minor hearing loss to the normal aging process. But when it continued to get worse, he went back. This time, audiologic testing revealed that he had completely lost certain frequencies.

"I was hearing strange noises - water sounds, squeaks. I called it my 'zoo' of noises. My PCP recognized this as a possible symptom of an acoustic neuroma."

An MRI revealed an 8-millimeter acoustic neuroma, small enough to wait for surgery. Ninev returned in six months but the tumor was continuing to grow at a faster pace than expected. "It's an anguishing decision," he said. "In my research, I learned that the longer you wait, the more risk there is for facial nerve damage and other complications when you do have the surgery," but he was glad his surgeon's mind did not spring directly to surgery.

Ninev reached out to the online acoustic neuroma community and found a wealth of information. "I learned that Vanderbilt Skull Base Center is a Center of Excellence for AN care. While it was the closest to me—a five-hour drive from my home in Indianapolis—it also came highly recommended. I wanted surgeons who had performed hundreds of these procedures."

At Vanderbilt, Ninev met neurotologist Alejandro Rivas and neurosurgeon Reid Thompson. "I knew I was in good hands. They were so open; they had a willingness to take the time and really explain things."

Because his tumor had grown to 1.1

centimeters and he had already lost 70 percent of the hearing in his right ear, the Vanderbilt surgeons decided to use the translabyrinthine surgical approach, one of several they offer.

"With this approach, we had a very good chance of preserving Mr. Ninev's facial nerve function," explained Rivas. "And we were successful. In translabyrinthine surgery, we go through the hearing channel, which provides the best view of the tumor; we don't have to push on the brain stem or cerebellum."

Ninev's care team emphasized the importance of safely and carefully re-establishing normal activities. He followed the required schedule of physical therapy and started doing frequent short walks, initially with a cane, to challenge his brain to adapt to a single remaining balance nerve. Two months after his surgery, he and his wife met friends in Yosemite for a long-planned hiking trip. And he began to think about returning to diving.

In his research, Ninev encountered the broadly held recommendation that AN patients (especially translab) should not return to scuba diving because of 1) the risk of cerebrospinal fluid leak 2) loss of or impaired ability to equalize the middle ear on the surgical side 3) risk of vertigo brought on by temperature changes and 4) risk of barotrauma to the only remaining hearing nerve.

"After carefully weighing the risks and experimenting for weeks in a pool, I decided to go back into the water. I started out slowly and have since gone on seven vacation dives. There's no better testament to my surgical team's expertise!"

Call our care coordinator at 615-936-4730 for help with taking the next step in your acoustic neuroma journey. Established treatment isn't good enough—you should have the option to take your life back.

We can help.

Sponsor Spotlight

VANDERBILT UNIVERSITY
MEDICAL CENTER

You or your loved one has just been diagnosed with an acoustic neuroma. We understand that you're looking for answers and you want them now—you want kindness, compassion, and efficiency. We can help.

Vanderbilt's Skull Base Center offers more than treatment options - we offer the kind of care that you deserve, delivered precisely at the time you need it. If you expect the best at one of the most uncertain times in life, call our care coordinator at (615) 936-4730.

We offer appointments with a top-ranked physician within one week, we accept self-referrals, and your coordinator will be there every step of the way.

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SPONSOR ARTICLE



You Are Not Alone

I thought my first symptom, hearing asymmetry, was normal age-related hearing loss. I'd noticed during phone calls that my right ear was weaker than the left, but my hearing was good overall. I was 52, and the asymmetry had been present for about a year.

That changed when I suddenly lost most of the hearing in my right ear. I checked for blockage, but it was clear. This was definitely not normal. I made an appointment and was seen by an ENT PA who recommended an MRI because of my ongoing tinnitus. The MRI confirmed that I had a 1.8 cm vestibular schwannoma. I decided right then to get to work finding the best-of-the-best docs for this.

When I learned about the UCSD AN team I was blown away. There was something about them that stood out, a certain *je ne sais quoi*. I wanted to talk to them at once, but it was late so I left a voicemail.

Kris, who is a Patient Navigator and AN patient herself, returned my call and the first thing she did was make sure I had her mobile number. We chatted for about 45 minutes, during which time I realized I wasn't alone.

I spoke to Dr. Rick Friedman the next day and after a few minutes of listening to him, I knew he was my guy. I recall the sincerity in his voice when I asked about the consult I'd be having that afternoon with surgeons at my local hospital, and whether I should cancel, knowing that I was leaning heavily toward the UCSD program. He advised that I keep the appointment but added "Todd, (pause) we do good things here." It was one of the kindest, most sincere things I've ever heard.

That afternoon I met the surgical team at my local hospital. They were impressive docs, and during our conversation I realized it would be convenient to have the procedure done locally. And then it hit me, convenience shouldn't be a factor in this decision. Experience and positive outcomes were paramount. The local team that I met currently performs about 15 AN procedures each year. Dr. Friedman and Dr. Schwartz were doing three a week, sometimes five, and had done thousands in their careers. They were my idea of the best of the best.

Two days later, Dr. Schwartz called and said I was a retro-sigmoid candidate. He reviewed certain risks with the

approach and I accepted them as a reasonable tradeoff for even a small chance (only 30%) to preserve hearing. Like Dr. Friedman, it only took a few minutes of listening to know that Dr. Schwartz was also my guy. He was no-nonsense but had a caring tenor in his voice, the kind that says he is going to help you with this.

We met in person for the first time during the pre-op visit and it was like seeing old friends. The interactions between these doctors spoke volumes about why they've been working together most of their careers. My surgery questions had already been answered in prior communications. I asked new questions that arose, but I mostly just listened and rested comfortably in their presence, as it reminded me that I'd made one of the best major decisions of my life. I was ready.

The first 12 hours after surgery were a wild ride. I made the best of it and soon, I was feeling better. All of my neuro ICU nurses and members ►

Sponsor Spotlight

UC San Diego Health

From the moment you contact the UC San Diego Health Acoustic Neuroma Program, we want you to feel truly cared for as a person. Our emphasis is on holistic care and life-long connection to our patients. We understand that managing a complex diagnosis like an acoustic neuroma goes beyond

just the date of treatment. We are a one-of-a-kind, comprehensive program, caring for patients from around the world. Our home is within the new, state-of-the-art Jacobs Medical Center, that provides patients with a safe and wonderful place to receive care. Dr. Friedman and Dr. Schwartz, who lead our treating team, have the largest combined AN experience in the US and they help each patient navigate their way through this

diagnosis and its care. We are thrilled to co-host the upcoming Patient Education Event with the ANA on June 19th and 20th in La Jolla, CA. We invite you to join us as we come together to share, educate and empower one another during this collaborative event. Register now at www.ANAUSA.org/UCSD.

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◀ of the AN team were top-notch, as was the Jacobs facility. I had slight facial paralysis for about 12 hours and headaches that were manageable with Tylenol, but my tumor was gone and I still had some hearing.

Once I was released, I walked and rested, A LOT. I did a sightseeing road trip to Seattle with my best friend at the wheel and I had asked Kris what to expect. She said other than feeling dizzy at first, I would quickly adapt, and she was right.

About two weeks after surgery, I was driving locally. I followed orders and kept my head above my heart for the first 20 days. The day after that I went

to yoga and carefully did forward folds and downward dogs. Woof!

By the fourth week the headaches faded and I felt ready to work. Seven weeks after surgery, I went skiing, starting with an easy slope and then moving on to something more challenging. That was all it took to know that I was back to being me.

It's now the new year. I do my PT balance exercises and I'm back to my pre-surgery exercise routine. My balance is off, but only slightly, and I occasionally have a day where I'm lower energy. But I'm early in the process and patiently optimistic for continued improvement over time. I've

learned from Kris and other patients' stories that we call this the new normal.

Day-to-day, I feel like the surgery never happened. And then, I remember hearing Dr. Friedman as I woke up. He gently said "We were able to save your hearing." That one brings a tear every time, including now, as I write this. I know I'm one of the few who shares that result, and for that, I shall remain humbled and grateful the remainder of my years. I'm happily living my new normal life, and I send my best to those of you about to join. You are not alone.

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Mayo continued from page 10

Quality of life issues include hearing and vestibular function. Certain surgical approaches can sometimes help preserve hearing after the removal of small- and medium-sized tumors. Vestibular rehabilitation, which involves practicing certain physical movements that help with balance, can also make a big difference. Our team at Mayo Clinic highly recommends that patients have vestibular testing and enroll in vestibular therapy.

What future developments might further improve acoustic neuroma management?

We've learned a lot recently about the natural history of the disease. Those advances will continue and will help us better determine when a small tumor can be observed over time. We also expect to see further advances in imaging, to give us a clearer view of the facial nerve.

In addition, we are learning more about the genetics of this disease

and the molecular features of these tumors. In 10 years, it's possible we will be able to inhibit the growth of acoustic neuromas biologically, and avoid surgery. Molecular therapies might also help us manage these tumors after surgery. Overall, we will continue to see improvements in acoustic neuroma care.

For more information visit mayoclinic.org/acousticneuroma.

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Sponsor Spotlight



House Clinic and House Ear Institute have officially relaunched as The House Institute. We strive to continue the groundbreaking work accomplished by founder Howard P. House and his brother William F. House over 60 years ago. Carrying on in their footsteps, The House Institute Ear and Neurosurgery Clinics provide world class care for acoustic neuroma patients. The House Institute Foundation works

concurrently, promoting surgeon education on the treatment of acoustic neuromas and performing groundbreaking, multidisciplinary research. Current acoustic neuroma research at House includes efforts to identify biomarkers for tumor behavior, using novel imaging technologies intraoperatively to improve surgical outcomes, and the development of novel, minimally invasive approaches to the internal auditory canal. "We are honored to continue the work that began with Dr. Howard House. Under our new identity as The House Institute,

we're making a commitment to remain on the front lines of research and innovation that will put our patients on the best possible path to leading normal, healthy lives for many years to come," said William Slattery, M.D., President of The House Institute.

Visit us online at www.houseclinic.com or find us on Facebook, Instagram, Twitter, and YouTube as House Institute.

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Voyages: Through Trauma Comes Strength *continued from page 1*

At first I thought it was a mistake. I thought the doctor would call and say he showed me the wrong person's scan. I even thought to myself, "I forgive him. This mistake could happen to anyone." Instead, I was soon sitting in a neurosurgeon's office and was told that in the coming weeks I would have brain surgery, which could mean losing half of my hearing, my balance, and potentially—my greatest fear—my smile.

With a 3.2X2.8 cm mass, surgery was the only choice. As a person with no history of health concerns, I was terrified. I was so used to caring for others, not the other way around. It was extremely overwhelming.

On Valentine's Day of 2017, I had a 10-hour surgery that successfully removed my entire tumor. I ended up with complete deafness in my left ear and ever-present tinnitus and I lost my balance, which I have since regained. I gained sensation back to my face and I was happy to have kept my smile, which I seem to be doing a lot of these days.

Although this experience was extremely challenging to cope with at the time, I reflect on this journey and I honor all that it taught me. I am sharing my story to provide hope to those who are going through something similar, or to those who are having a hard time moving forward after a similar trauma.

I think the most important thing I've learned is to have compassion for myself. It is important to give yourself the same love and support you would give to a friend who is going through a hard time. Take time to do things you enjoy, to rest and rejuvenate, to honor your feelings and cope with them in a healthy way. Personally, I started meditating and journaling two weeks after my surgery and I continue to do this every day. I have been able to become more present in my day-to-day life—journaling ten things I'm grateful for each morning— even small things as simple as the comfort of my bed or the smell of my coffee. This experience also gave me the opportunity to revisit my values and to truly understand what's important in life.

To me, that is health and wellness, work/life balance, personal growth, and connection to a higher power of my own understanding. Yours may not be the same, but I do invite you to take this opportunity to see what aspects of your life are most important and how this challenge may help you to see things differently.

After many hours with a counsellor and group therapy, I have found healthy ways to cope with and truly face the trauma that interrupted my beautiful life. I have come out on the other side, not with harm, but

with skills to help me live an even more fulfilling life.

I have focused on aspects of my health that I can control and have lost 57 pounds, transforming my entire body. I am back to nursing now, working with premature infants in the NICU. My hearing loss made me terrified that I would miss a heart murmur or a crackle in a neonate's chest. But, I've learned that I can lean on others for support, and what I lack in my hearing, I make up for in compassion. In many ways, losing my hearing has helped me become a better listener, more focused and more understanding to the struggles of others, whatever they may be.

Losing my balance has helped me live a more balanced life. And losing my hearing has helped me listen to the voice within. This may not be your season for hustling and grinding, but it is your reason to rest, restore, connect with yourself and others, and to find the beauty in the pain that you are experiencing.

Give yourself time.

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