

Notes

A publication of the Acoustic Neuroma Association



ACOUSTICNEUROMA
ASSOCIATION

IN THIS ISSUE

Medical Report 4
Patient Stories 7
Support Groups 11
Research 12

Navigating an AN Diagnosis

The ANA began as a way for acoustic neuroma patients to connect with, and learn from, each other. Though we do much more than that, we still hold connecting and informing patients as our chief mission. If you're new to the ANA community or are looking to engage more deeply, visit anausa.org/community for more helpful resources.

Support Groups

Find a group that fits your demographics, location, or experience. These groups meet regularly as a way for patients and acoustic neuroma medical providers to learn from each other. We offer both in-person and virtual meetings.

Community Connections

These informal meeting opportunities, organized by ANA volunteers and held in local communities, offer casual networking time and encouragement, as well as support through shared experiences.

One-on-One Support

Peer mentors are acoustic neuroma patients and family members/caregivers who are willing to talk about their acoustic neuroma experience. These volunteers provide information, encouragement, and support to other acoustic neuroma patients via telephone, email, and video.

Discussion Forum


Visit our message board at anausa.org/forum to connect with other patients and members of the AN medical community.

INTERESTED IN GETTING INVOLVED?


Contact us at 770-205-8211 or volunteers@anausa.org to learn more about volunteering.

CONNECT


You can also connect with us and find more resources on social media. Tag us in your posts or send messages directly to our pages—there is a lot of support in this community!

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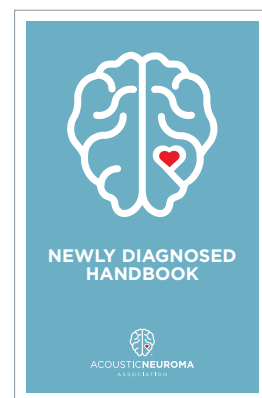
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Navigating the Road Ahead

The initial diagnosis of acoustic neuroma is overwhelming, but we have a resource to help.

The *Newly Diagnosed Handbook* can help you better understand acoustic neuromas, and assist you in navigating your diagnosis. You can also find an overview of the brain and nerve anatomy relevant to these tumors, as well as tests that may be ordered, and the type of healthcare providers involved in a patient's care.

Additionally, learn about the importance of tumor size, treatment options, decision making, choosing a doctor, and more.



GET YOUR COPY TODAY

This publication is free to ANA members and can be viewed in the member section of the ANA website. To request a print version, please contact us. Non-members can visit anausa.org/shop to order online.

Join the ANA for Upcoming Events

AN AWARENESS WEEK 2024

JUNE 16-22

Presenting Sponsor - Akouos

Visit anausa.org/awareness for more information.

PATIENT EDUCATION EVENTS

VIRTUAL EVENT

Saturday, April 27, 2024

10 a.m. to 12:30 p.m. ET

Hosted by Mount Sinai

Visit anausa.org/mount-sinai for more information.

FULL-DAY, IN-PERSON EVENT

Saturday, October 5, 2024

Hosted by Pacific

Neuroscience Institute

Los Angeles, California

Visit anausa.org/pni for more information.

SEEKING VOLUNTEERS

The Acoustic Neuroma Association is seeking exceptional volunteers to serve on our national Board of Directors—specifically volunteers 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 help provide oversight and execute the strategic plan.



If you're interested in learning more about this opportunity, please contact **Melanie Hutchins** at melanie@anausa.org for more information.

Tips for Navigating a New Diagnosis

Find the right healthcare provider for you. The ANA provides a searchable listing of healthcare providers on our website. Visit anusa.org/providers to search by name, location, or keyword.

Bring a list of questions to ask your doctors. Many people find it helpful to create a list of questions prior to appointments. Information can be overwhelming, so take notes, have a friend or family member accompany you, or use your cellphone's voice recorder to help recall information. You can also visit anusa.org/questions to download and print the ANA's *Questions to Ask*.

Attend the Newly Diagnosed/Pre-Treatment support group. This group meets monthly. When you register for a meeting, you can submit your top three questions to the ANA's staff and volunteer facilitators. Limited spots are available, and advance registration is required. Visit anusa.org/upcomingevents for more information.

Have a support system. Think about the people in your life who will be supportive, and consider specific ways they can help. We also encourage you to attend ANA support group meetings and connect with a peer mentor. To connect with any of the volunteers or peer mentors featured in this issue, or if you are considering a treatment option and want to speak to a volunteer with a similar experience, please contact us. You can also view a list of peer mentors on the ANA website in the member section, using the search tool to refine your selections. Visit the ANA's discussion forum at anusa.org/forum for additional online support.

Visit the ANA video library. For educational presentations on treatment options and decision making, visit the website video library at anusa.org/video-library and search by topic. More videos are available in the member section.

Remember, this can be an emotional time. People experience a wide range of feelings about acoustic neuroma. The way you feel today may be different than the way you feel tomorrow. Our booklet, *Understanding Emotional, Cognitive, and Behavioral Changes* provides information and strategies to help you navigate complex emotions and seek out helpful resources. This publication is free to ANA members and can be viewed in the member section of the ANA website. To request a print version, please contact us. Non-members can visit anusa.org/shop to order online. ♥

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How Doctors Make Decisions

Helping patients navigate diagnosis and treatment

By Steven A. Gordon, M.D., M.P.H. and Myles L. Pensak, M.D., F.A.C.S.

Discovering you have an acoustic neuroma can be overwhelming. It's an uncommon tumor, and most patients have never met another person with AN or heard of it prior to diagnosis. For many, the first thing they do is research AN on Google. However, sifting through all of that information can be incredibly challenging, as there are often conflicting answers to the same questions.

Your physician is there to provide information, recommendations, and guidance regarding your AN and treatment options. We are also striving to tailor a recommended protocol to you rather than tailoring you to a protocol that is pre-established. The ultimate treatment decision comes down to the patient's own value system of risks and benefits.

For physicians like us who are fortunate enough to work in a large medical center with a vast and diverse patient population, and who have access to colleagues with unique and unparalleled expertise, our recommendations are made by consensus of many experts. This allows us to collaborate and consult with colleagues in multiple surgical or medical specialties and collectively decide what is best for you.

Factors in Decision Making

Age: When determining treatment options, one major decision-maker is your age. AN patients can be in their 20s, in their 70s, and everything in between. A tumor in a 12-year-old that is 1cm in size is very different than a 1cm tumor in an 85-year-old. These tumors tend to grow slowly, at a rate of 2-3mm per year on average. Therefore, age is a key variable when presenting treatment recommendations.

Nature of your symptoms: How your symptoms present is another determining factor in the treatment decision. If you happen to have been hit by a ball, and someone ordered an MRI during which a 1mm AN in your internal auditory canal is discovered, this is an incidental finding. This is vastly different when compared to someone who suddenly becomes profoundly hearing-impaired. Patients may present with face pain due to compression of the fifth cranial nerve (trigeminal nerve) by a large AN. They may have debilitating vertigo. They

may have no symptoms at all. All these factors play a role in determining a treatment plan.

General health: Other determining factors about treatment pertain to a patient's general health. A small AN in a 25-year-old triathlete is very different from a small AN in a hypertensive person with diabetes. While they both have the same size AN, it is a very different algorithm that we use in terms of what we recommend.

Size, location, consistency: The size of the AN is another important consideration. A 5mm AN and a 5cm AN are the same tumor biologically, but there is a huge difference in recommended treatment. Similarly, a 1cm AN found only in the internal auditory canal (IAC) is quite different compared to a 1cm AN in the cerebellar pontine angle (CPA) compressing the brainstem. Additionally, purely solid ANs versus ANs with large cystic components also play a key role in decision making.

Hearing status: Another consideration is the hearing status of both ears. If a tumor is on a patient's only hearing side, this presents a very difficult and different decision for the patient and physician when compared to someone with perfect hearing in both ears. Similarly, if a patient has hearing on the AN side, compared to a patient with no hearing on the AN side, this will significantly impact the decision algorithm.

Personal obligations: A semi-retired person with a 1cm AN who is financially independent is in a very different situation than a 31-year-old single parent with minimal health insurance who has a 3cm tumor. These life circumstances require different approaches to treatment.

Lifestyle matters: A patient that is a mountain climber may have a different treatment recommendation than a patient with a more sedentary lifestyle.

Individualized Treatment

Given any one of these scenarios, there are a series of options available that vary from individual to individual.

Observation is always a possibility with small and medium-size tumors. There is rarely an urgency to remove an AN. But what does observation mean? Physicians may use hearing tests to follow changes in a patient's hearing, and your physician may recommend a series of MRI scans, which can be done at six-, nine-, or 12-month intervals. When there is no growth, observation continues.

The reason we like to wait at least six months is because it takes time to see clinically-significant growth on the MRI. In other words, *if* the tumor is going to grow, you must give them time to grow. Once no growth has been documented, we can start to space out the frequency of MRIs. However, we will continue with additional MRIs because most tumors do not grow linearly. They may grow, then lay dormant for years, and then start to grow again. It is important to always monitor the AN.

In most centers, radiation is an option with tumors under 3cm. Whether or not you have single dose (radiosurgery) or fractionated (radiotherapy), treatment is similarly individualized for the right patient, the right tumor size, and the right location.

When we discuss radiation, we are referring to a targeted dose of radiation to the tumor. This is *not* the type of radiation we think of for many other tumors, which require treatment every day for six weeks—there are no radiation burns or immediate side effects. The patient will feel the same before and immediately after radiation. Additionally, the goal of radiation is to stop the tumor from growing. It does *not* shrink the tumor or make it go away. There are a multitude of radiation delivery systems and brand names that provide stereotactic radiation/radiosurgery such as GammaKnife, CyberKnife, and LINAC (linear accelerator). While this might sound confusing, all these approaches are nearly identical, with minor differences in pros and cons. They largely provide the same outcomes, risks, and benefits.

Another treatment option is surgery. Sometimes removing the entire tumor is the best option. Sometimes removing only part of the tumor, followed by radiation or observing the remnant, may be the best option. Size, location, and a patient's health all play key roles.

Patient preference is also a key factor when it comes to surgical treatment. Some patients have significant anxiety knowing they have an AN, and having it removed would give them peace of mind. Surgery is the only treatment that removes the tumor. However, like each treatment option, surgery comes with significant risks and benefits that must be tailored and discussed with the patient.

There is no one-size-fits-all when deciding treatment...Be informed, be confident, and establish a relationship of mutual respect and trust with your treating physicians.

Your First Appointment

How should you plan for your first consultation?

To begin, educate yourself using information gathered from reputable organizations and websites such as the Acoustic Neuroma Association. For patients that want specific details and studies, they can review literature on PubMed*. Educating yourself will provide you with knowledge, as well as help you and your physician communicate more effectively and have a commonality of language.

Before meeting with your physician, collect and review all your information, and prepare a list of questions, using your symptoms as a guide. For example, what about the tumor is most bothersome to you? Additionally, consider questions from your family and friends, and add those to your list.

Make sure that you understand the salient, important points, and request clear descriptions and explanations that are not in “physician-speak.” Moreover, there is nothing that says a decision or plan must be made in a single office visit—in most cases, ANs do not require emergent care.

You may be wondering, what is the physician's perspective on treatment? It's safety first, safety second, and safety third. Ultimately, we understand this decision is centered around quality of life, and it is a thoughtful mapping out of what is best for the patient who is sitting in front of us.

It is important when meeting with a physician—whether it's a radiation oncologist, ENT surgeon, neurosurgeon, or internist—that your treatment is individualized to you. If you feel you are being forced into a decision or formula, it's time to start walking. If you are with a group of physicians who are trying to optimize and tailor an outcome and protocol just for you, then you are in a medical center that has your best interests in mind.

There is no one-size-fits-all when deciding treatment. And it is important to note that for most tumors, there is no right or wrong decision. We want to provide enough information to prevent the “woulda, shoulda, coulda” phenomenon—feeling you should have had surgery when it was small, or you should have observed it over time, or you should have had radiation, etc.

In conclusion, be informed, be confident, and establish a relationship of mutual respect and trust with your treating physicians. ♥

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A Guide to Informed Decision-Making

Courtney C.J. Voelker, M.D., Ph.D. (DPhil Oxon)

Receiving a diagnosis of acoustic neuroma (AN) can be overwhelming and frightening. However, taking an active role in your healthcare journey is crucial to ensuring the best possible outcome. As an AN patient, becoming educated and preparing for your appointments is essential for making informed decisions about your treatment.

Preparing for Your Physician Consultation

Compile a comprehensive list of symptoms. Start by listing all the symptoms you've been experiencing, no matter how minor they may seem. Symptoms can vary widely, including hearing loss (gradual or sudden), tinnitus, balance issues, dizziness, facial weakness or twitching, facial numbness, and others. Note the frequency and severity of each symptom, as well as when they first appeared. This detailed information will be invaluable for your physician in understanding your condition.

Document the impact on your life. Describe how your symptoms are affecting your daily life. Are they interfering with work, relationships, or hobbies? Be specific about the challenges you face. This will help your physician gauge the urgency of your treatment and tailor their recommendations accordingly.

Choosing the Right Physician **Consult with experienced**

AN specialists. AN is a relatively rare condition, and not all physicians have equal expertise in its diagnosis and treatment. Seek out specialists who have experience in treating acoustic neuromas. These specialists include neurotologists (a subspecialty of ear, nose, and throat surgery), neurosurgeons, and radiation oncologists.

Seek recommendations.

Ask your primary care physician for recommendations or referrals to an AN specialist. Additionally, consider seeking out support groups such as the ANA or online forums where AN patients share their experiences and recommend physicians.

Verify credentials. Ensure that the physician you choose is board certified and has a history of successful AN treatment. You can also inquire about their experience and ask for patient testimonials or case studies.

What Your Physician Needs to Know

Your medical history. Be prepared to discuss your medical history, including any previous surgeries, medical conditions, or medications you are currently taking. This information can impact your treatment options. Have all medical records related to your AN ready for the physician. This should include all hearing tests (audiograms) and imaging (MRIs and CT scans). Your physician will evaluate your level of hearing and whether your tumor is growing or staying stable over time. Your physician may order more tests in order to help you make a treatment decision.

Your goals and concerns. Clearly communicate your treatment goals and any concerns or preferences you may have. An open and honest dialogue with your physician will help tailor your treatment plan to your individual needs.

Becoming an Educated Patient **Research acoustic neuroma.**

Take the time to educate yourself about acoustic neuroma. Understand the anatomy of the inner ear, internal auditory canal, and cerebellopontine angle where the AN grows. Read about the various treatment options available (surgery, radiation therapy, or observation), and the potential risks and benefits associated with each.



Reliable sources of information include medical journals, reputable websites, and books written by experts in the field.

Ask questions. Do not hesitate to ask your physician questions during your appointments. Write down your questions in advance and bring them with you. Knowledge is empowering, and your physician should be willing to address your concerns.

Consider a second opinion. Seeking a second opinion can provide you with additional perspectives on your condition and treatment options. It can also help you make a more informed decision about your care.

In summary, being an informed and proactive acoustic neuroma patient is vital for managing your condition effectively. Remember that you are in control of your healthcare journey, and your active involvement can lead to the best possible outcome. ♥

Courtney C.J. Voelker, M.D., Ph.D., (DPhil Oxon) is a Rhodes Scholar and board-certified neurotologist. Dr. Voelker is the director of otology/neurotology lateral skull base surgery and the director of the Adult & Pediatric Cochlear Implant Program at Pacific Neuroscience Institute in Santa Monica, California. She is a member of the Acoustic Neuroma Association Medical Advisory Board.

CyberKnife Was the Right Choice for Me

Mark McLaren, peer mentor and support group co-leader, Palo Alto, California

My AN journey started many years ago in 1991, when I noticed changes in my hearing. Three years later, an audiogram confirmed some unilateral high-frequency hearing loss in the right ear. For the next several years, there were occasional comments about my hearing loss at my regular physical exams.

In 2001, an audiogram confirmed that my hearing had deteriorated in the high-frequency range. The audiologist was more proactive, and I had an MRI which revealed a 2cm acoustic neuroma. I searched the Internet, and my wife and I began to review treatment options and formulate our list of questions.

Neurosurgeons suggested surgery and dismissed any discussion of radiosurgery. They proposed the translab approach, which would destroy my remaining hearing. After further discussion, they decided that the retrosigmoid/suboccipital approach would give me some chance at retaining my existing hearing.

I have world-class medical centers in my area and decided to have additional consults to help me make a final surgical decision. This is where my AN journey took a turn. At my next consultation, the physician asked why radiation was not a consideration. I told him I had concerns, such as having follow-up MRIs for the rest of my life, as well as the risk of radiation-induced malignancy and the possibility of a more difficult surgery if the radiosurgery wasn't successful.

The physicians responded to my concerns, and in my subsequent research, it appeared that radiosurgery could be as effective as surgery. I also found that there was limited scientific evidence of radiation-induced cancer. Additionally, my



Mark biking Mt. Diablo, the tallest mountain in the San Francisco Bay Area.

MRI follow-up protocol would be the same regardless of which treatment I chose. And, if I did require a second treatment down the road, it would be more challenging no matter my treatment choice. Though there were risks, there was also very little evidence that surgery after radiation would be more difficult in the hands of an experienced surgeon.

This new information gave me more to think about—a position in which every AN patient eventually finds themselves. No treatment option guarantees a perfect outcome or zero risk, and I asked if I could speak with patients that had been treated with the CyberKnife, which I found invaluable. In 2001, I made my decision and had CyberKnife treatment.

The procedure was anticlimactic compared to the process of getting there. I took a week off and rested. I experienced some episodes of vertigo and double vision soon after treatment. Undoubtedly, this was due to some tumor inflammation from the radiation, which was not unusual, but still disconcerting.

These issues cleared up, and things have been uneventful since. It has been 23 years since my treatment, and the results have been very positive. I couldn't be happier, and I am very thankful for wonderful physicians and the CyberKnife. ♥

To find ways to connect to other patients and hear more stories from your peers, visit anasa.org/community

Surgery Gave Me My Life Back

Erin Heidrich, peer mentor, Cincinnati, Ohio

I was diagnosed with an acoustic neuroma on July 30, 2020, and for the first few nights after my diagnosis, I didn't sleep at all. I was frantically searching the Internet hoping to find someone who would tell me I didn't actually have a brain tumor or, at the very least, tell me how to get rid of it and go back to my real life. But I quickly learned that there is no one "right" way to resolve an acoustic neuroma. No one was going to tell me what to do. I was going to have to make some tough decisions.

My tumor was small when I was diagnosed—7mm, which meant I had some time. My next MRI was in six months, so I took time to explore both radiation and surgical options, hoping that maybe I would be one of the lucky ones whose tumor never grew.

Radiation, an outpatient procedure, was appealing. But I was only 38, and I worried about long-term effects. Surgery presented its own risks, most importantly to my hearing.

After six months, I learned that my tumor was growing. During my watch-and-wait time, I realized that the most important thing to me was to try to preserve my hearing. Since hearing preservation surgery



Erin and her husband, Karl Preissner

was more likely to be successful while the tumor was still small, I decided to move forward with surgery.

The ANA's discussion forum was helpful in gathering information about surgeons and surgical outcomes. I looked for a

team that had performed many acoustic neuroma surgeries. I also wanted to minimize risk to my facial nerve. Finally, I wanted to minimize my time under anesthesia. After meeting with eight surgical teams, I chose to have middle fossa surgery at UC San Diego.

My tumor was removed on July 13, 2021. Surgery lasted four hours, and my facial nerve was perfectly preserved. Unfortunately, my hearing in my right ear was lost. While I was disappointed, I did not question my decision. I had done the research and was satisfied. I had given myself the best chance for success based on what was important to me.

There are many ways of responding to an acoustic neuroma diagnosis. Surgery is not the right choice for everyone, but it was the best choice for me.

The immediate post-surgical period was difficult as I learned to navigate hearing loss and worked to regain my balance. I received an Osia hearing implant in January 2023.

Ultimately, surgery gave me what I was looking for in those early, frantic days—it gave me my life back. ♥

CONNECT AND DISCUSS

We recently reached out to our social media community and asked them to share any encouraging advice they might have for newly diagnosed patients. Here's what they had to say.

Focus on the emotional/mental challenges of dealing with post-surgery "stuff." The physical side gets better naturally.

—John

Get a second opinion about treatment options from a provider who specializes in AN. Don't be opposed to traveling for the right provider.

—Carol

I would suggest not rushing to make a plan. Take your time to ponder your choices.

—Melodee

You are the CEO of your body, so it's up to you to communicate with all doctors in your journey so they can help you.

—Kathy

12 Years of Watching and Waiting

Ginnie Ferraro, support group leader and peer mentor, Denver, Colorado

In 2012, I noticed ongoing fullness in my right ear, as well as difficulty hearing on the phone. My ENT reviewed my symptoms, and I tried antibiotics and anti-inflammatory medications to rule out an acute episode in that ear. Over time, none of these medications were successful at relieving the symptoms, so an MRI was ordered, revealing a 5mm x 6mm acoustic neuroma. My initial thought and reaction to this news was, of course, “Wow—I have a brain tumor!”

I’m a nurse, so naturally I wanted to learn more about this tumor and treatment options. Fortunately, my tumor was small. And since most ANs grow slowly, I had time to do my research. My husband and I were fortunate to attend the ANA’s biennial symposium that year, hosted by the House Clinic in Los Angeles. There were many speakers discussing all aspects of treatment and care, and we gathered information and asked many questions.

I met with one of the House Clinic physicians who reviewed my MRI and tests, and based on the size of my tumor, made an initial recommendation of watch-and-

wait. I joined the ANA, began attending support group meetings, read all the informative literature, and listened to all the webinars. I also sought out other opinions and recommendations, visiting several physicians and radiation centers.

During that time, I felt watch-and-wait was right for me, and my physicians were recommending this as well. My tumor was small, with mild hearing loss and tinnitus. I didn’t have headaches, and my balance was good, even when playing tennis.

I evaluated the treatment options and potential side effects. I was concerned my symptoms might exacerbate with treatment, and so today, I continue to monitor my tumor. I see my ENT every four months, have an audiogram every six months, and have an MRI every two years. These tests are helpful for monitoring any changes.

After all these years, there has been minimal growth. And if I were to have any dramatic changes in symptoms, my ENT would order an MRI to check for changes in tumor size.

Throughout this journey, there were several things that I found helpful, such as compiling a list of all my questions,



Ginnie and her new grandbaby

receiving several opinions about my treatment options, weighing the pros and cons of each option, and attending ANA support meetings, which provided tremendous emotional support.

I am so thankful for the ANA and continue to learn from all the information they provide. If my condition were to change, I would be prepared.

For the past seven years, I have volunteered as a peer mentor and the leader of the Denver support group. I learn so much from our support group participants as we share experiences and resources. I appreciate the positive support that we provide for one another, and I hope you will join us at a meeting soon! ♥

Join the ANA. They’re a wealth of information. Join a Facebook support group. They can be your lifeline in the storm. Educate yourself about ANs and get multiple opinions until you find a team you are comfortable with. Prepare for treatment and recovery in advance. Be your own best advocate. This is a difficult diagnosis to deal with on all levels, so be gentle with yourself.

—Paula

Slow down, relax. You’ve got this, and everything is going to be okay.

—Bernie

Do your research, and ask a lot of questions. You need to feel confident in YOUR choices, because at the end of the day, certain choices are yours. Have honest and open conversations with your family, because everyone in the household will be affected and deal differently. As hard as it may be, be open to accepting help as you need it.

—Sherry

If you’re experiencing anxiety and fatigue, know that it’s real. Be kind to yourself.

—Jennifer

In Conversation

Speaking with Helen McHargue, support group co-leader, San Diego, California

Acoustic Neuroma Association: What has surprised you most about volunteering?

Helen McHargue: How beneficial the meetings are for the attendees and for me! I encourage others to volunteer because I feel it can be an instrumental part of the healing process. I've also been amazed by how knowledgeable the attendees are, and how willing they are to share their knowledge.

Before my role as a co-leader, I never thought of myself as the support group type, but I was having difficulty coping with my SSD after CyberKnife radiation in 2009. I'd joined the ANA and received information about the support group meetings, but I made excuses for not attending. Finally, despite my disequilibrium, I drove through a California downpour to the meeting in San Diego. The speaker was excellent, and I met several people with whom I could relate.

After almost everyone left, I noticed the leader was folding up chairs and putting them away, and I couldn't believe no one was helping her. After we finished, I had such a sense of satisfaction both for attending the meeting and helping accomplish this small task. I rarely missed a meeting after that, and eventually, I became a co-leader.

ANA: What do you wish other people knew about the ANA?

McHargue: How much accurate information they can get from the resources available at the ANA website. Also, the many benefits that accrue in support groups from sharing your victories and setbacks with others who understand.

ANA: Can you share a special support group memory?

McHargue: It's hard to pick just one. When your group rallies around someone who needs support—that's the best. Also, it's great when everyone pulls together, and others step forward to help in a big way, like my co-leaders, Margaret Briggs and Melissa Diaz, who will continue the group after I "age out." I am grateful to have younger co-leaders who can keep abreast of new developments in our changing, digital world.



Helen McHargue

VOLUNTEER

If you want to help others on their AN journey, being a support group leader is a great way to get involved. We have resources that make it easy, and we are here to help you every step of the way. Email Melanie Hutchins at melanie@anusa.org for more information.

ANA: What would someone be surprised to know about you?

McHargue: I'm 82 and still active despite SSD, tinnitus, and minor disequilibrium. I exercise, still drive on the freeways (although less often), recently organized our house remodel, and still manage a small business from home. Although I'm still active, I'm purposefully slower (avoiding falls is a major concern at my age), and I make sure I get enough sleep. I schedule downtime every day to recharge my batteries.

ANA: What would you tell someone who is thinking about volunteering?

McHargue: Volunteering is a most satisfying way to spend your time. Now that I'm in my eighties, I think about spending time like spending money. You've only got so much—use it wisely!

ANA: What do you do when you aren't volunteering?

McHargue: I volunteer more! I'm active with my local library. I fold clothes and help organize merchandise at local thrift shops, and I'm on the board of my Homeowner's Association. I also belong to a great book club and a wonderful writing group. I garden, and my husband and I travel extensively.

ANA: Can you share a tip that helped you during your AN journey?

McHargue: My new normal after diagnosis and treatment is now my NORMAL. I can't remember what life was like physically before the AN. You become a different person once you adapt to a handicap. A few other tips:

Hearing. If, like me, you have decent hearing out of the non-AN ear, you learn to arrange yourself in groups, so your hearing ear faces the action. It always makes me laugh at in-person support group meetings when everyone rearranges their seating as the room fills.

Balance. One of the best balance tips when shopping is to grab a shopping cart immediately. The cart helps keep you steady. It's also noisy, so people can hear you, and it's easier for others to see you in the parking lot.

Tinnitus. Mine is non-stop 24/7, so I keep my brain distracted. It's the only thing that really works for me.

You should be the motivating force in trying to find solutions to your challenges. Try not to wear your partner out, and be kind to each other. I have my own ways of coping, but my husband's steadying arm has been the most helpful and comforting factor during my AN journey. I feel so very lucky to have him.

ANA: What inspires you to engage with and support the ANA?

McHargue: I stay supportive because I continue to learn from other patients and because the ANA is so incredibly helpful, especially for the newly diagnosed. ♥

SUPPORT GROUPS

2023 SUPPORT GROUP HIGHLIGHTS

Over the past year, the ANA has continued to expand its network of support groups, providing a variety of options for your convenience, including geographic groups, virtual groups, and co-sponsored groups with our medical partners. Our meetings are always free, and include guest speakers, panel discussions, informational presentations, networking time, and more.

We wish to thank all of our 2023 support group leaders and co-leaders, all of whom are acoustic neuroma patients or care partners. We invite you to visit anasa.org/support-groups for more information.

HERE'S WHAT OUR PARTICIPANTS ARE SAYING

I am grateful that the support group leader made time to speak with me so quickly, and that you follow-up with this extra care. I hate to imagine where I would be without the ANA during this experience.

—Laura

Honestly, I felt amazing after seeing many extremely supportive and kind people on the support group Zoom yesterday.

—Mitchi

How can the ANA and the volunteers be thanked enough by the patients and caretakers? The experience of the group showed me something of the unexpected differences each patient needs, and posed new questions for me.

—Barney

It is very uplifting to hear others who have experienced or who are experiencing similar life changes.

—Jeanelle

I have been so pleased with the meetings I have attended. The group leaders are wonderful.

—Earle

BALANCE ISSUES, DIZZINESS, AND VESTIBULAR THERAPY

- Managing Balance Issues
- Physical and Vestibular Therapy
- Post-Treatment Imbalance Issues
- Vertigo

COGNITIVE/EMOTIONAL

- Anxiety and Depression Associated with Watching and Waiting and/or Tumor Regrowth
- Caregiver Fatigue
- Medical Trauma and Coping with Anxiety
- Neurocognitive Effects of Acoustic Neuroma

DECISION MAKING, TREATMENT OPTIONS, AFTERCARE

- Aftercare (Pain Control, Timeline for Hospital Stay)
- Modern Management of Acoustic Neuroma
- Surgical Management: Different Strategies for Different Sizes
- Tackling the Top 5 Issues in AN/VS Management: A Patient Centered Approach
- Treatment Options and Decision Making

EYE ISSUES AND CARE

- Eye Care and Scleral Lenses

FACIAL ISSUES AND REHABILITATION OPTIONS

- Facial Nerve Preservation
- Facial Reanimation Options
- Facial Synkinesis
- Foundations of Facial Retraining
- Neuropathic Facial Pain

GENERAL AND GROUP DISCUSSION

- AN Case Presentations and Panel Discussion
- Headache Management
- Navigating the Workplace/ Employment Concerns
- Q&A - Ask the Docs

HEARING ISSUES, DEVICES, AND TINNITUS

- Hearing Device Demonstrations and Q&A with MED-EL and Cochlear Americas
- Hearing Loss and Cognitive Decline
- Hearing Technology Options
- Overview of Hearing Aids and Devices
- Tinnitus Management

REGROWTH

- Regrowth Rates and Management Protocol

RESEARCH/ ON THE HORIZON

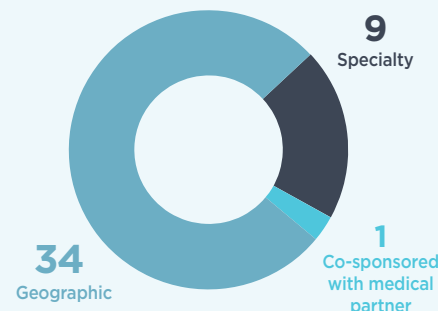
- Advanced Technologies in Skull Base Surgery: Augmented Reality
- Washington University St. Louis Observation Study



Visit anasa.org/video-library to view recorded virtual presentations. More videos are also available in the member section webinar library.

2023 ANA SUPPORT GROUPS BY THE NUMBERS

SUPPORT GROUPS



Support Group Attendance

1,500

53 support group leaders/co-leaders

114 support group meetings

MOST POPULAR EDUCATIONAL TOPICS

- Hearing Loss / Devices / Technologies
- Balance Issues / Vestibular Therapy
- Treatment Options
- Facial Issues / Rehabilitation

19 presentations recorded and added to the ANA video library

ONLINE SUPPORT

ANA Discussion Forum

1,936 1,006

new users

new posts

Closed Facebook Support Groups

16 moderated by ANA staff and volunteers

RESEARCH GRANTS

The ANA Awards \$75,000 in Research Grants for 2023

The Acoustic Neuroma Association's commitment to research continues as a strategic priority for our organization, as evidenced by the \$75,000 awarded through our 2023 Research Grant Program.

"The quality of proposals we receive continue to represent strong, creative projects, and we're broadening the impact of the ANA's research investment," says Samira Rajabi, Ph.D., chair of the ANA Research Committee. "This work is so important for today's patients, and for those who will receive their diagnoses tomorrow."

The following research projects will receive funding through the ANA 2023 Research Grant Program:

University of California, Los Angeles (UCLA) will receive a two-year, \$50,000 grant to evaluate EMP2's (a protein-coding gene) expression in primary acoustic neuroma/vestibular schwannoma samples, while also aiming to utilize transcriptomic data to correlate the expression of EMP2 with inflammatory, immune, and angiogenic markers. The research will also evaluate the effects of anti-EMP2 treatment in tumorsphere models.

The researchers' goal is to contribute to the current understanding of the molecular mechanisms involved in acoustic neuroma/vestibular schwannoma tumorigenesis. The aim is to lay the foundation for a new therapeutic target. Based on the results, anti-EMP2 therapy could ultimately become a safe and minimally-invasive treatment option and present a great step toward individualization of treatment.

Mayo Clinic has been awarded a \$25,000 grant to continue a previously-funded research effort. The earlier project included 2,000 ANA members and Mayo Clinic patients participating in a prospective quality-of-life survey. A team of experts, including representatives from neurotology, neurosurgery, audiology, survey design, statistics, and patient advocacy then created a new disease-specific instrument to measure quality of life: the Vestibular Schwannoma Quality of Life (VSQOL).

This additional grant will allow for expanding the quality-of-life efforts to translate the VSQOL Index into other languages to enhance participation in, and reduce the potential of, inequitable access to quality-of-life research. Researchers see translation efforts improving the lives of vestibular schwannoma patients in the U.S. and worldwide by increasing inclusivity in research to comprehensively evaluate the impact of a diagnosis of vestibular schwannoma and its treatment on well-being and quality of life.

The ANA is additionally committed to funding \$146,000 in research through partnerships with Keck School of Medicine (USC), UC San Diego Health, Mount Sinai, UC San Francisco, Emory University, and Washington University St. Louis, bringing the total for multi-year research grant funding to \$221,000. ♥

THE ANA RESEARCH COMMITTEE

Samira Rajabi, Ph.D., chair
Neil D. Donnenfeld, MBA
Nancy Fisher, Ph.D.
Hela Kelsch, D.O.
Mary Ann Mugel, M.S.N., R.N., A.O.C.N.
Chad Nye, Ph.D.



In addition to informing and connecting the AN community, *NOTES* serves as a journal for medical research findings regarding acoustic neuroma. Visit anusa.org/research for more information on our work in this area.

SPONSOR SPOTLIGHT

VANDERBILT HEALTH

At Vanderbilt Health, we make healthcare personal.

Our Skull Base Center offers a multidisciplinary team of experts who tailor a treatment plan for each patient. From a watch-and-wait, radiation, or surgical approach, to hearing, balance, and facial nerve issues, we are leaders in researching and treating acoustic neuroma.

A patient care coordinator is at the center of your Vanderbilt Health acoustic neuroma experience—scheduling appointments, collecting medical records, and answering questions. Your treatment team also includes neurosurgeons, neurotologists, ENTs, radiologists, facial plastic surgeons, physical therapists, and audiologists. In addition, we have neuroanesthesia specialists and a unique 35-room neurosurgical ICU.

When diagnosed with an acoustic neuroma, you have many questions, and there are multiple treatment options to consider. Our patient care coordinator can set up an appointment within one week to help you begin to find the best path to wellness.

Call 615-637-3639 or visit VanderbiltHealth.com/acousticneuroma to learn more.

THE OHIO STATE UNIVERSITY WEXNER MEDICAL CENTER

The thought of losing your hearing or suffering from constant ear ringing can be scary, as well as detrimental to your overall quality of life. These symptoms can be especially concerning when they're caused by an acoustic neuroma.

Fortunately, the physicians at the Ohio State University Wexner Medical Center have been evaluating and treating patients with acoustic tumors for decades. Our team proudly provides a multidisciplinary approach to patient care, combining the efforts of otolaryngology, neurosurgery, audiology, radiation oncology, and neurology to ensure you receive the safest and most optimal outcomes.

We offer extensive experience in all three surgical approaches for acoustic neuromas and take every necessary step to preserve your hearing and the hearing nerve. For select patients with acoustic neuromas, we also offer clinical studies and trials that can help restore hearing using cochlear implants.

Meet with our team today to develop your unique treatment plan. Visit go.osu.edu/acoustic-neuroma or call 614-366-3687 for more information.

UC San Diego Health

The UC San Diego Health Acoustic Neuroma Program provides unsurpassed AN care to patients across the country and around the world.

We are experienced. Rick Friedman, M.D., Ph.D., and Marc Schwartz, M.D., have performed more than 2,000 surgeries together. They are experts in all three surgical approaches and in the use of radiosurgery.

We are unique, offering holistic, comprehensive care that includes vestibular therapy and osteopathic treatment to promote healing and patient comfort, as well as advanced hearing implant options. Because we offer all treatment options, we are able to help patients better understand and decide which treatment is best for them.

We are compassionate. Our team includes patient navigators who have been through AN surgery, and who can share their experiences, helping to guide patients through diagnosis, treatment, recovery, and follow-up care. We also offer complimentary, no obligation phone consultations.

We are committed to advancing hearing preservation when appropriate. In addition, we successfully perform a growing number of AN surgeries with simultaneous cochlear implants.

Everyone at the Acoustic Neuroma Program of UC San Diego Health wants you to feel truly cared for, from your first contact and for the rest of your life. Visit <https://health.ucsd.edu/care/ent/acoustic-neuroma/> for more information.



Located in Beverly Hills, Los Angeles, Cedars-Sinai's Acoustic Neuroma and Lateral Skull

Base Tumor Program delivers personalized care and excellent outcomes for challenging cases that many other centers consider untreatable.

Our program's directors, John S. Yu, M.D., and Mia Miller, M.D., highly value their partnership in the operating room. As a neurosurgeon, Dr. Yu is specialized in the workings of the brain and monitoring neurological function. As a neurotologist, Dr. Miller possesses a deep understanding of bone anatomy and the locations of nerves.

Our team also includes a vestibular expert, a facial nerve and plastic surgery specialist, audiologists, and physical therapists. We also have a dedicated patient navigator to help you and your family navigate the various appointments, pre-op testing, and tours of the hospital, remaining at your side throughout your treatment journey.

Email us at acousticneuroma@cshs.org or visit our website to learn more.

SPONSOR SPOTLIGHT



At Northwell Health, we understand the complexities and challenges of acoustic neuroma. Our program, led by a team of world-class specialists, provides comprehensive care tailored to each patient's unique needs.

Northwell's approach combines cutting-edge technology with compassionate care. We offer a range of treatments, from microsurgery to advanced radiosurgery techniques, ensuring the most effective treatment plan for each patient.

Northwell Health's neurosurgery team excels in microsurgery, employing meticulous techniques and state-of-the-art equipment to ensure precision, minimizing the impact on surrounding neural structures during acoustic neuroma removal. Beyond medical treatment, our team focuses on the patient's overall well-being, offering support through rehabilitation services, counseling, and patient education.

Our program includes a multidisciplinary neurosurgery team comprised of subspecialized radiologists, neuropathologists, and neuro-oncological specialists. These experts collaborate closely to provide an accurate diagnosis and develop a personalized care plan for each patient to achieve the best possible outcome. Northwell Health emphasizes convenience for patients, striving to offer services in one location when possible.

Our commitment to research and advancement in acoustic neuroma treatment places us at the forefront of medical excellence. Northwell Health not only provides life-changing care, but also contributes to the global understanding of acoustic neuroma.

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 We very much appreciate their
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We cannot recommend doctors, medical centers, or specific medical procedures and always suggest that one consult with a physician before making any medical decisions.

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UC San Diego Health



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