Back to Adventure

Ninev Karl Zia looks forward to his adventure vacations. In his early 50s, Zia enjoyed biking, mountain trail hiking and boating. In 2014, he had even learned to scuba dive. Then he started noticing problems with the hearing in his right ear.

Zia consulted his primary care physician, who attributed his minor hearing loss to the normal aging process. But when it continued to get worse, Zia returned to his physician. 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 acoustic neuroma.

see Adventure, page 10

Two Opinions: One Decision

BY THOMAS SATTLER, M.D.

In 1989, I noticed that the dial tone on my phone was not the same pitch in each ear despite perfect hearing. I saw an ENT who did the standard hearing and balance tests, all of which were normal. However, an MRI revealed a 1.0 cm acoustic neuroma. It also revealed a second benign brain tumor, a meningioma. Because meningiomas frequently require no treatment, I was advised to watch the meningioma but decide what I wanted to do about the AN.

see Two Opinions, page 2
I began exploring my options. I decided to have the AN removed rather than watch and wait because of my professional plans as a dermatologist. I was planning to leave the HMO medical group where I practiced and accept an offer to start a private practice with an established dermatologist. But, before leaving the HMO practice, I wanted to be sure I would be okay to continue to practice. So I proceeded with the surgery.

I selected a neurosurgeon in a different city. The tumor was removed with a middle fossa surgical approach. The surgeon felt he had removed the entire tumor even though the post-operative MRI revealed a small dot at the internal auditory canal. He thought the dot was just a blood vessel and could be watched on subsequent MRIs. Two months later I returned to work, and a month thereafter I accepted the offer to start my own practice.

I continued to have regular follow-up MRIs. Two years after surgery, the “dot” was unchanged but the meningioma had begun to grow. I was advised to have it removed while it was still relatively small, so I had a second craniotomy to remove the meningioma. Then, within another two years the “dot” began to enlarge—the AN had recurred. My doctor and I decided to follow it rather than re-treating, hoping it would cease growing, but eventually it filled the entire internal auditory canal. When a very small portion began to grow out of the canal, the neurosurgeon who had removed it initially recommended repeat surgery, which I scheduled.

Before the scheduled surgery date, however, I had an appointment with the neurosurgeon at the nearby medical center who had been ordering the MRIs and following my case. After reviewing all the MRIs, he suggested I wait an additional nine months and repeat the MRI. Then, only if it continued to grow should I have surgery.

So, I had two well-known neurosurgeons suggesting completely opposite courses of actions. I, the individual with the least experience and knowledge, had to decide what to do. After lots of anxious contemplation, I decided I really did not want a third craniotomy, and if an experienced neurosurgeon thought it was safe to wait, I would do so. I cancelled the surgery. A few days later, the first neurosurgeon called to ask why I cancelled the surgery and encouraged me again to have it removed. It was a very difficult phone call, but I explained my decision and held firm.

The MRI nine months later showed no growth. Subsequently I have had MRIs every two years and the tumor has remained stable...until six years ago when the tumor started to shrink!

The neurosurgeon who suggested I defer surgery pending another MRI retired before that MRI was done, so he never knew the result. Then, fifteen years later, at a recent ANA support group meeting, I saw the name of the man who signed in just before me. It was that neurosurgeon! I was shocked. I introduced myself and gave him the follow up details of my case. He gave me a “high five” and we clapped hands high in the air. What a wonderful opportunity to thank him for his advice!
CEO’S MESSAGE

THANK YOU TO THE ANA TEAM

I have been with ANA now for about 18 months, and in that short time, I have come to learn a great deal about acoustic neuroma and the many people who make this organization work. The ANA Board of Directors is comprised of 18 individuals—16 patients, 2 spouses of patients, coming from a wide array of backgrounds and areas of the country, who ensure that ANA continues to serve the AN community at the highest level of service possible. They are among the most caring, thoughtful, and dedicated board members with whom I have ever worked.

The illustrious group of medical providers who serve on the ANA Medical Advisory Board have proven to be continuously willing and able to answer questions, provide medical information, and support ANA. In addition, I am humbled that so many enthusiastic volunteers—Support Group Leaders, ANetwork Volunteers, Discussion Forum Moderators, and fundraisers—give their time, talents, and energy to help others. Finally, I am so proud of the small but mighty staff of ANA; these ladies work so hard, and together form a team of which I am proud to be part.

We have gotten a lot accomplished in the past year and a half, and I am excited about the future of ANA. Please mark your calendar for ANAwareness Week, May 7-13, 2017. I want to encourage you to join us, to get involved with this amazing organization. In the meantime, I look forward to continuing to learn together.

Best,
Allison Feldman

ANA VOLUNTEERS

Over 130 ANA volunteers, serving in various capacities across the United States, dedicate their time and energy to supporting the mission of the Acoustic Neuroma Association. We are very thankful for their commitment to ANA and the support, education and outreach they provide to the AN community.

These caring individuals serve as ANA ambassadors, contributing their skills to ensure that patients have information, encouragement and moral support. Whether they provide meeting opportunities in their community, phone and email support through the ANetwork Program, or moderate the ANA Discussion Forum 24/7, they are ready to provide a personal connection.

Have you been inspired by the great work our volunteers do and want to contribute your skills? Maybe a special volunteer made all the difference in your acoustic neuroma journey? Let us know how meaningful and valuable our volunteers and these programs are to you. Contact Melanie Hutchins, Manager of Volunteer Programs, at volunteers@ANAUSA.org, and thank you for your feedback.

See page 8 for a Recap of the most recent ANA support group meetings.
Acoustic Neuroma (AN) arise from the vestibular nerve. These are benign tumors with overall growth of 1-3mm/year. Patients present with a variety of symptoms including hearing loss, vertigo, and tinnitus, and in larger tumors with symptoms of brainstem compression, weakness, numbness, other cranial nerve deficits and possibly hydrocephalus. Occasionally, patients are incidentally diagnosed after an MRI is done for other reasons.

For newly diagnosed AN, the current management options include observation, stereotactic radiosurgery (SRS), and microsurgery. While microsurgery is the preferred treatment for tumors larger than 3 cm, a conclusion has not been reached with regard to a superior management strategy for small- to medium-sized tumors. As a result of increased availability of MRI screening, patients are now being diagnosed earlier in their disease course and an optimal treatment strategy for the small- to medium-sized AN is becoming increasingly important. Parameters such as tumor growth and recurrence and preservation of hearing and facial nerve function are used to compare the success of observation, SRS, and microsurgery in treating AN. In addition to clinical outcomes, quality of life after treatment and cost-effectiveness also play a role in choosing the best management strategy for the patient.

Observation is considered a viable option for smaller lesions that are incidentally discovered in patients who are asymptomatic, the elderly, or patients who are averse to treatment. Some studies with longer follow-up periods suggest that growth rates could be higher than above mentioned rate of 1-3mm/year and do not necessarily occur at a steady rate. The factors that influence AN growth are not completely understood. Incidental tumor can be most often watched initially. The wait-and-see strategy is the classic recommendation for managing small AN, but improved techniques for SRS and microsurgery and studies with longer follow-up times are causing surgeons to move away from this idea. A recent study by Regis et al. indicates that conservative management of small AN exposes patients to a significant risk of tumor growth or hearing loss, and therefore suggests a more aggressive approach to small tumors with proactive radiosurgery. Failure was observed in 35 patients out of 47 undergoing conservative management as the tumor grew or hearing worsened. Chances of retaining functional hearing were much higher in the group of patients treated with SRS compared to the group of patients managed with the wait-and-see strategy. Microsurgery was not specifically addressed in this study.

Microsurgery is the only treatment option that completely removes the tumor, while SRS stabilizes/controls tumor size and observation only monitors tumor growth. Over the past few years, there has been a dramatic trend in the treatment paradigm of AN. More tumors are being treated with SRS, and more surgeries are resulting in subtotal resections. The rationale behind this dramatic shift is the cranial nerve function preservation. Patients’ quality of life should be carefully assessed and every attempt should be made to preserve function. It is evident that a total resection of AN increases the risk of facial nerve palsy and hearing loss specifically in larger tumors. Advanced neuromonitoring and nerve monitoring techniques are being used to advise the surgeon intra-operatively on the status of cranial nerve function. Regardless, neurosurgeons have become cautious and most often aim for a near-total resection, leaving the most adherent part of the tumor attached to those cranial nerves. Studies have shown that tiny residual tumors rarely grow significantly, or else can be addressed.
with SRS. The main practical issue with this novel surgical strategy is "when to stop the resection of the tumor." The frustrating aspect for surgeons is as follows: whether they aim for near-total resection, leaving some tumor behind to not risk function and yet the patient wakes up with profound facial nerve deficit, or the surgeon is too conservative and removes, very partially, the tumor which would be characterized as subtotal or partial resection. Even if the function is preserved, the post-operative imaging is somehow disturbing with significant residual tumor. So how can one find that sweet spot?

This question brings up the value of subspecialty training and a comprehensive multidisciplinary approach to patients with AN. Patients with AN are undoubtedly better managed in specialized centers where every individual’s situation is discussed within a multidisciplinary team and a consensus regarding the best management option is agreed upon. Here is how our management algorithm is designed:

Totally asymptomatic patients with no cranial nerve deficit should be watched unless if the patient is young (<60 year old) and has a larger tumor (>3cm). Symptomatic patients with smaller tumors (<2.5cm) are best treated with radio surgery (SRS). However, our recent study showed that these patients could also have excellent outcome with microsurgical resection both in terms of facial nerve function preservation and hearing. Surgical expertise and experience plays an important role in this decision making.

For larger tumors (>3cm), microsurgery is usually the treatment of choice. With thorough neurosurgical techniques and experience, the vast majority of patients can benefit from a near-total resection and preservation of both facial and hearing nerve integrity. There is no scientific limit between a near-total or a subtotal resection. In general, a near-total resection is considered more than 95% resection. Patients should specifically ask about their surgeon’s estimation of what is a subtotal resection. A subtotal resection leaving a significant portion of the tumor (anything more than 20% in our point of view) is sub-optimal. The decision as to leave <20% or very tiny residual, or a complete anatomical resection depends on the intra-operative findings and the surgeon’s judgment. There is no question in our mind that leaving a small residual is better than a profound facial nerve weakness after surgery. This strategy can only be applied when there is a substantial experience in both surgical technique, and decision making intra-operatively. An additional five minutes of dissection can divert an excellent outcome into a poor outcome as far as the facial nerve or hearing nerve function are concerned. Having said that, the surgeon’s initial resection objective should be as complete and safe as possible. We believe that a very conservative surgical approach is not helpful and puts the patients at evident risks for further treatments and sometimes early re-surgery for residual tumors.

The above mentioned discussion is with regards to physician’s perspective. But what about the patient’s decision and judgment in AN treatment? Patients play a crucial role in the surgeon’s decision as long as he or she has an understanding of the pros and cons of each treatment modality. We often follow our patient’s preference in terms of treatment modality, and even more so for the microsurgical strategy. The surgeon’s confidence also plays an important factor here.

In our experience, microsurgery for smaller tumors (<2.5cm) have resulted in a very high rate of facial nerve preservation (>95%) and a gross total resection in vast majority of patients. For larger tumors, we tend to err on the side of near-total resection if a clear plane is not identified between the nerve and the tumor. Preservation of the facial nerve integrity and hearing nerve integrity is important even if the hearing is not functional. The latter will help for a cochlear implant option if considered in patient’s future management. This is particularly important in neurofibromatoses patients in whom a bilateral hearing deficit can result in deafness.

Finally, the cost of patient management should be carefully evaluated. Strategies which protect the patient against potential complications and do not mandate follow-up routine imaging at short and long term are preferred. In carefully selected patients, microsurgery remains the treatment of choice for AN.

Overall, the management of AN has significantly evolved over the past decade, not only because of the advances of SRS in this field, but also due to better understanding of surgical complications, refinement of surgical techniques and monitoring, and modification of surgical strategy in AN as outlined above.


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

"Patients play a crucial role in a surgeon’s decision as long as he or she has an understanding of the pros and cons of each treatment modality."
Headache that persists for months or even years after acoustic neuroma surgery (chronic phase) can be debilitating and may be an under-appreciated complication of acoustic neuroma treatment. While chronic headache may occur in patients after any type of craniotomy, the incidence of headache following acoustic neuroma surgery has been noted for many years to be higher than after craniotomy for other causes.

The exact prevalence and causes of chronic postoperative headache (POH) are elusive. There are several reasons for this. First, the reporting of factors that affect quality of life rather than mortality and objective signs of morbidity is a relatively recent phenomenon. Second, headaches are common in the general population at baseline. Third, reports from dedicated headache centers rarely offer significant detail regarding operative approach or nuances, while reports from individual surgical centers cannot be said to be generalizable to the population of acoustic neuroma patients as a whole. Also, the experiences and biases of surgeons and others involved in the treatment of acoustic neuromas often lead them to radically different opinions and conclusions regarding the issue of headache in acoustic neuroma patients.

**HEADACHE PREVENTIVE MEDICATIONS**

Chronic headache preventive medications are used to decrease headache frequency or severity while minimizing adverse reactions. Preventives are often started if headaches occur more than 1 to 2 days per week. The oral formulations are taken on a daily basis. These preventive medications do not necessarily treat the origin of the pain (as do steroids post-surgically). The goal of headache preventive medication is to decrease the headache frequency by 50%, and it takes at least two months at the target dose or maximally tolerated dose to know if a headache preventive is going to be useful.

None of the medicines are a panacea. None stand a good likelihood of making a person’s headaches go away entirely. It is important to establish reasonable expectations. Physicians could prescribe higher and higher doses of medicines until somebody stops complaining that they are experiencing episodes of headaches. But it is very likely that the side effects, including things like drowsiness, or cognitive difficulties, or even emergence of depression symptoms would be more problematic than a low level of headaches would be. Thus, it becomes a balancing act between side effects and effective treatments. There is no “one size fits all” answer. In general, a care provider prescribes a preventive based on the characteristics of the headache that the patient has.

**LOCAL THERAPY TO NECK MUSCLES**

In cases of headache resistant to medical treatment, local therapy applied to the neck muscles may be effective in many cases. This includes physical therapy with stretching and range-of-motion exercises, local heat application, massage and biofeedback to learn muscle relaxation techniques. On occasion, a “trigger point” can be identified in the cervical muscles, which appears to be a source of pain and tenderness. Local injection of an anesthetic or steroid at this site can occasionally provide substantial temporary relief of pain.

**ACUPUNCTURE AND COMPLEMENTARY TREATMENTS**

Acupuncture is a widely used therapy for a variety of medical problems, among them headache. While anecdotally patients appear to have significant improvement, rigorous clinical testing of efficacy is limited (based on Western Medicine methodology – randomized placebo controlled trials). Not surprisingly, there are no studies specific to the acoustic neuroma post-craniotomy headache population. In the chronic phase of pain management, the goal is to reduce the perception of pain. This can be accomplished with traditional or non-traditional methods. Even so, not all patients may experience a benefit with any given treatment. Eastern medicine therapies and their derivatives such as acupuncture, relaxation techniques, yoga, massage therapy and biofeedback may benefit some but not others, even if only by consistently providing a placebo effect.

**STRESS REDUCTION AND ANTIDEPRESSANTS**

Clearly, the occurrence of severe debilitating headache after acoustic
neuroma surgery creates a tremendous amount of stress. This can exacerbate and perpetuate the headache and reaction to pain in an ever increasing cycle. In addition, chronic pain produces profound alterations in the chemistry of the brain, and this often is manifested as overt clinical depression. For these reasons, it is important that patients with severe headaches after acoustic neuroma surgery seek additional care to treat the psychosocial aspects of the disorder.

Family, co-workers and health care providers need to understand the severity of these headaches and their associated impact on lifestyle and ability to function. Professional counseling is imperative when the headaches are producing disability or significant depression. Many antidepressant agents also are excellent adjuncts to therapy of chronic pain and should be prescribed in conjunction with other therapies.

**MULTIDISCIPLINARY PAIN CENTER OR HEADACHE SPECIALIST**

In the most treatment-resistant cases, it may be necessary to treat post acoustic neuroma surgery headaches in a multidisciplinary pain center. These centers are dedicated to treating chronic debilitating pain, and combine the talents of neurosurgeons, anesthesiologists, physical medicine specialists, psychiatrists and physical therapists. Because acoustic neuroma headaches are caused by a variety of different factors, treating the problem fully frequently requires an intensive, combined approach such as that provided in a multidisciplinary pain center.

**LIFESTYLE FACTORS AND HEADACHE MANAGEMENT**

Lifestyle is also important and there are things that make headache frequency less, and can reduce the severity of headaches. Lifestyle changes are not easy, but also don’t have a lot of side effects.

Getting regular sleep is an important factor that is commonly overlooked, and one that can really pay a lot of dividends in relation to headache. Getting onto a regular sleep schedule and getting adequate sleep during the night can reduce a person’s overall headache burden. If a person has severe snoring or sleep apnea, getting appropriate evaluation and treatment can improve a person’s quality of life. The same goes for eating regularly. It is not uncommon that somebody who is in the workplace will say, “Well, I don’t really eat breakfast, I get into work and, depending on the day, I may miss my lunch, or I may only have five minutes to eat my lunch. And so I’ll just have a power bar and a soda, or something. And then, I’ll make it up. I eat a healthy dinner. I feel like I’m overall meeting my nutritional needs during the day.”

However, having dietary intake spread irregularly over the day like that can be a problem for somebody who is experiencing headaches. It can make headaches more severe and more frequent. Scheduling your caloric intake regularly over the course of the day can help to minimize headache burden. Hand-in-hand with this is making sure to remain adequately hydrated.

Stress management is something that’s easier to say than it is to do. But, stress is certainly another potential trigger for headache, and another area where better management is also good for our general health. Stress management can also reduce the reliance on medications that are being used to achieve the same effect. Sometimes it is recommended that a person get psychological consultation to try to identify better methods of stress management. A person may not even be aware of the sources of stress in their daily life.

There have been studies, even looking at biofeedback, trying to understand what is it during the day that really is contributing to our stress, and this has actually shown a reduction in headache frequency and severity. That underscores the importance of being attentive to our internal state; being attentive to the things that we do that we find stressful during the day. This can help to put the management of headache back into your own hands, and can empower you to gain better symptom control.

For some people there can be environmental triggers for headache. Certain odors, or foods, or different environmental exposures may make headaches more likely. Again, this is another aspect in which we can put the control of these headaches back into our patient’s hands. Recognition and avoidance of triggers for these patients can be helpful at decreasing headache burden.

Excerpts taken from Headache Associated with Acoustic Neuroma Treatment: An ANA Patient Booklet. The full publication can be found on our website in the Member Section at www.anausa.org.
ANA SUPPORT GROUPS - 2016 SUPPORT GROUP MEETING RECAP

HIGHLIGHTS INCLUDED:

**Alternative Medicine**
- Alternative Medicine and Integrative Practices to Help with AN Issues and Challenges
- Finding the Way: Integrating Holistic, Nutrition and Alternative Medicine Approaches in your AN Healing Process

**Balance Issues**
- Balance Issues and Treatment Options, Group Discussion on Tips and Strategies for Short-Term and Long-Term Management
- Coping with Balance Issues Associated with Acoustic Neuroma
- Exercise Interventions for Acoustic Neuroma: Balance and Facial Paralysis
- KEEP CALM and BALANCE ON - Coping with Balance Issues Related to Acoustic Neuroma
- Maintain a Good Sense of Balance, The Vestibulo-Ocular Reflex (VOR), Treatment Options and Exercises
- Tai Chi for Balance, Exercise and Stress Reduction, Presentation and Demonstration
- The Importance of Balance Training
- Vestibular/Balance Therapy Before, During, and After AN Treatment, Helpful Exercises
- Vestibular Issues and the Importance of Balance Therapy Vestibular Therapy for Acoustic Neuroma Patients

**Caregiving**
- Caregiving Issues and Strategies, What to Know, What to Ask, How to be Supportive - Before and After Treatment

**Coping / Cognitive**
- Cognitive Decline Associated with Untreated Hearing Loss
- Coping Strategies to Help Couples, Family and Friends Dealing with an Acoustic Neuroma
- Positive Psychology - A Path to Lasting Happiness and Positive Thinking
- Pre- and Post-Treatment Neurological Issues Associated with Acoustic Neuroma

**Eye Issues / Eye Care**
- Eye Care for Acoustic Neuroma Patients

**Facial Issues and Rehabilitation Options**
- Exercise Interventions for Acoustic Neuroma: Balance and Facial Paralysis
- Facial Plastic and Reconstructive Options for Acoustic Neuroma Patients
- Medical (Botox) and Surgical Options for Facial Nerve Issues
- Treatment Options for Facial and Eye Issues Affecting Post-Surgical Acoustic Neuroma Patients

**General / Group Discussion**
- Acoustic Neuroma - A User's Guide, Sharing our Experiences in Living with an Acoustic Neuroma
- Acoustic Neuroma Patient Education Day
- Answers to Your Acoustic Neuroma Questions: Panel Discussion and Q&A Session
- Understanding Acoustic Neuromas

**Headaches**
- Headaches and Headache Management

**Hearing Issues / Devices / Tinnitus**
- Acoustic Neuroma and Single-Sided Deafness (SSD): Issues and Solutions
- AN and Hearing Rehabilitation: A Current Overview of Technology and Options
- Communication Strategies and Assistive Devices for Acoustic Neuroma Patients
- Coping with Hearing Loss and Tinnitus Associated with Acoustic Neuroma
- Coping with Tinnitus - Treatments and Options
- Group Discussion - Hearing Related Issues and Strategies
- Hearing Device Options for Acoustic Neuroma Patients
- Hearing Loss: Causing more harm than you realize? Helpful communication strategies for living with hearing loss and tinnitus with the use of a BiCROS/CROS hearing device
- Hearing Rehabilitation Options and Tinnitus Management
- Newest Advancements in Hearing Aids/Devices
- Novel Strategies to Manage Hearing Loss and Tinnitus
- Ototrain Device for Tinnitus Relief Information and Demonstration
- Tinnitus and the Mindfulness-Based Therapy for Tinnitus Reduction
- Tinnitus Management
- Tinnitus Solutions and New Treatment Options

**NF2**
- Merlin: Not your Average Wizard! How NF2 Research is Helping Discover Drug Therapies for Acoustic Neuroma
- Brain Tumor Imaging

**Treatment Options**
- Acoustic Neuroma Case Presentations and Panel Discussion
- Acoustic Neuroma Treatment Options, Expected Outcomes & Post-Treatment Issues to Consider When Making a Decision
- Current Treatment Options for Hearing Loss for Patients with Acoustic Neuroma
- Decision Making in Acoustic Neuroma Treatment
- Evolving Treatment Strategies for Acoustic Neuromas
- How Does Anyone Really Decide the Best Treatment for an Acoustic Neuroma?
- Latest Developments in Radiation Treatment for Acoustic Neuromas
- Overview of Radiation Treatment Options
- Radiosurgery Explained: Answers to Questions You Didn’t Dare Ask
- Radiosurgery Results for Vestibular Schwannomas/Acoustic Neuromas; Treatment Options for Recurrent Meningiomas
- Stereotactic Radiosurgery: Facts and Controversies
- Tour of Gamma Knife Center; Overview of Gamma Knife Technology
- Treatment Approaches for Acoustic Neuroma and Hearing Options after Surgery
- Treatment Options for Large Acoustic Neuromas and the ANSRS (Acoustic Neuroma Subtotal Resection Study)
- When the First Time is Not Enough - Retreatment Options

CHECK OUT OUR VIDEO LIBRARY

Our video library, featuring presentations from our support group meetings, is available on our website. Also be sure to “Like” ANA’s Facebook page to view support group meetings broadcast via Facebook Live at https://www.facebook.com/ANAssociation/

To receive regular updates about these educational opportunities as well as other events and programs, please join our email list. Contact ANA for more information. ANA would like to thank the guest speakers, support group leaders, co-leaders and volunteers who help make these educational opportunities possible.
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An MRI revealed an 8-millimeter acoustic neuroma, small enough to wait for surgery. Zia returned in six months for observation but the tumor was continuing to grow. “It is 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.”

Zia reached out to others on the ANA Discussion Forum and found a wealth of information. “I read about other patients’ positive experiences at the Vanderbilt Skull Base Center. 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 many of these procedures.”

At Vanderbilt, Zia 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% of the hearing in his right ear, the Vanderbilt surgeons decided to use the translabyrinthine surgical approach.

“With this approach, we had a very good chance of preserving Mr. Zia’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.”

Zia’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 the ANA forum, Zia encountered the broadly held recommendation that AN patients (especially translab) should not return to scuba diving because of the risk of cerebrospinal fluid leak, impaired or loss of ability to equalize the middle ear of the surgical side, risk of vertigo brought on by temperature changes, and 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.” Zia states, “I started out slowly and have since gone on seven vacation dives. There is no better testament to my surgical team’s expertise!”

In no case does ANA endorse any commercial products, surgeon, medical procedure, medical institution or its staff.
It is hard to believe that anyone would call having a benign brain tumor requiring surgery a blessing but that is the way Robin Hand, a House Clinic patient, describes her experience. “I did not choose to have a tumor, however, I did get to choose my physicians and hospital for treatment. This experience and journey wasn’t something I had to endure. The journey has been a blessing in my life and an investment in my future,” Robin Hand explained.

Although she had difficulty driving for eleven years, and intermittent balance problems, it was when the ringing in her right ear started that Hand decided to go to an ENT. Her hearing test was normal but a MRI showed an acoustic neuroma. As a trained nurse practitioner, Hand did her homework to research her treatment options. “Everything I read indicated that you need a place that specializes in treating acoustic neuromas and performs a large number of these surgeries,” said Hand. “When I found the House Clinic online, I knew that I needed to get a second opinion.”

She sent her MRI to the House Clinic Acoustic Neuroma Center at St. Vincent Medical Center in Los Angeles for a second opinion. “When determining the course of treatment for an acoustic neuroma, it is important to remember that very few situations are urgent and there is usually time to get multiple opinions,” said Dr. Eric Wilkinson, surgeon and partner at the House Clinic. Their joint decision was to watch, wait, repeat the MRI in six months and re-evaluate.

The next MRI showed the tumor had grown. Since her hearing test was still normal, Dr. Wilkinson advised that due to the growth of the tumor, surgery was necessary “fairly quickly” for a chance to save her hearing. Three weeks later, Hand flew to Los Angeles for surgery. She credits the House Clinic surgeons, the internist, and the St. Vincent operating room staff and the nurses, for creating such a positive healing environment. “Having a medical background, I scrutinized everything and was continually impressed with the outstanding level of care I received. I know my great outcome is because I went to the best place,” said Hand. Dr. Wilkinson and Dr. Marc Schwartz, House Clinic neurosurgeon, were able to completely remove the tumor as well as preserve her hearing.

“Every case is unique and our vast experience with a large volume of patients allows us to be prepared for any specific situation,” said Dr. Schwartz. “All members of the team including not only the surgeons but also the anesthesiologists, nurses and therapists are focused on acoustic neuroma treatment.” Although she experienced some balance issues immediately after surgery, Robin attended a concert in Los Angeles on day eight. Hand went back to work full-time six weeks after surgery.

“Robin had an outstanding outcome, what all of us in this field strive for and which motivates us. She was ahead of the curve, not everyone is ready to go to a concert right after surgery, and continues to be an inspiration,” said Dr. Wilkinson.

“I’ve had years of struggling with not feeling well when driving, even to the point of car sickness, and thinking I was having anxiety related to a previous auto accident. What a blessing to be able to get in the car and enjoy driving again,” said Hand.
LEGACY SOCIETY

ESTATE DONATIONS: REMEMBERING ANA, HELPING OTHERS

ANA is grateful to Mary F. Snyder of Lake County, Indiana, for remembering our organization in her estate planning.

ANA was recently named as a beneficiary in Mrs. Snyder’s Last Will and Testament and her thoughtful gift makes it possible for ANA to continue to provide many programs and services for AN patients for years to come.

Mrs. Snyder is now the 20th member of the Acoustic Neuroma Legacy Society marking the society’s tremendous growth since its establishment in 2013. In such a short period of time, the members of this special group have made an enormous impact by committing to help ANA fulfill our mission for future generations.

If you are interested in joining the Legacy Society by including ANA in your financial and estate plans, please contact Jennifer Farmer at development@ANAUSA.org. We will gladly provide you with information on how to support ANA through your will, a bequest or a life insurance policy.

There is no time like the present to plan for the future!

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