Issue 140, December 2016

ACOUSTIC NEUROMA ASSOCIATION NOTES

Ask the Docs Q&A

ANSWERS PROVIDED BY FRANCO DEMONTE, MD, FRCS, FACS AND PAUL W. GIDLEY, MD, FACS

Q In a healthy patient with an AN that is 1.7 cm in size is radiation a viable treatment option?

A The short answer is yes. Deciding on a particular treatment for AN is highly individual, especially for medium-sized tumors (1.5 to 2.5 cm). If this 1.7 cm tumor has been observed to increase in size over time, some intervention should be performed. After considering age, general health status, and quality of hearing, the final choice between surgery or stereotactic radiotherapy is often an individual preference

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A Tale of Two Acoustic Neuromas

BY CELESTE AND DAVID VENTNERS

This is a story of not one, but two acoustic neuroma experiences. What is unique about this story is that the two subjects happen to be married.

Celeste's story:

For years I had been experiencing terrible headaches that had gotten worse. I also experienced dizziness when I turned my head quickly and had a major

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Young Mother's Story

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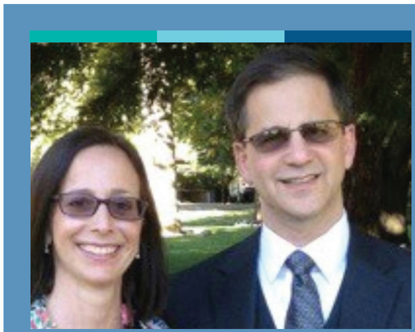

Legacy Society

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Ask the Docs

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Each treatment approach entails possible risks or complications. The patient must be willing to accept the risks of the chosen treatment.

Q Surgery for AN is highly invasive. Why would a patient choose it over radiation?

A Large tumors (more than 2.5 cm) generally require surgical intervention. Small tumors (less than 1.5 cm) can be observed, removed surgically, or treated with stereotactic radiotherapy. Medium-sized tumors, especially when observed over time and found to grow, will need some treatment. This treatment is either surgery or radiotherapy, and the decision is often up to the patient to decide. Some patients cannot stand the thought of having a tumor inside their head, and they want surgery to remove it. Other patients cannot fathom the idea of a surgical intervention that opens the cranium, and so they want radiotherapy. Each option has its own risk profile. Whichever treatment is chosen, the patient must be willing to accept the risks of the chosen treatment.

Q If there are no life-altering symptoms, is there a specific reason to seek treatment for an AN?

A Asymptomatic tumors are now being discovered much more frequently than in the past due to the wide availability and use of MRI. Many patients have MRIs for unassociated reasons, and an acoustic neuroma is discovered. The treatment plan depends on many factors, but the most important factor is the size of the tumor.

Q Why did my acoustic neuroma swell months after stereotactic radiation and then shrink after another year?

A This is not uncommon! It is important to recognize in order to avoid unnecessary interventions. The outlook remains good in all likelihood. Continued follow-up is recommended.

Q Is subsequent hearing loss more likely the result of radiation or the swelling from the radiation?

A These factors are related and the ultimate hearing outcome is likely a combination of both factors.

Q It has been six months since I underwent gamma ray treatment. Will I still be subject to facial drooping?

A Complications from stereotactic radiosurgery are rare, but if they do occur, tend to be delayed. Symptoms can appear as early as three months post-treatment or as late as nine months to a year following radiation. These symptoms are usually temporary.

Q I was diagnosed three years ago with a 3 mm, which has shown no growth. My doctor suggests I start spacing the MRIs further apart which makes me nervous. Do you recommend I have yearly MRIs for the rest of my life or would you be comfortable telling a patient to space them out longer if stable?

A We currently recommend yearly MRIs for five years, then every other year. There is really no widely accepted guideline that outlines the frequency or length of follow-up. Common sense dictates that these tumors should be checked occasionally for any signs of growth. Any reasonable schedule is fine.

Q Can you have surgery after having had radiation if the tumor regrows?

A Yes. Surgery following radiation therapy for tumor growth is certainly technically possible. Most surgeons feel that the outcomes for facial nerve function are not as favorable in this setting and hearing preservation is rarely, if ever, possible.

Q Is it possible to repair the acoustic nerve after surgical damage?

A No.

Q Once the hearing is gone could it come back?

A If the hearing loss is due to damage to the acoustic (cochlear) nerve, hearing recovery does not occur.

Thank you

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PRESIDENT'S MESSAGE

Holiday Greetings and Happy 35th Anniversary to ANA!

We are very excited about achieving this milestone and look forward to what the future holds! We have had an amazing response from ANA members and volunteers in celebration of the anniversary and we have enjoyed receiving so many unique stories of the positive and often powerful impact that ANA has had on AN patients and their loved ones throughout their unique AN journeys. We have more celebrations planned and we especially want to hear about how ANA has impacted your AN journey!

The ANA Board of Directors and staff have embarked on a strategic plan for ANA that is due to be completed in the spring. We really appreciate those of you who participated by taking the survey, which will help us to plan for the future. We have been working hard on developing the plan and look forward to sharing it with you in early 2017.

We hope that you are enjoying the new format for the newsletter, which allows additional pages, full color options and more flexible formatting and organization, all at a significant cost savings to ANA! If you have topics that you would like to see presented in the newsletter, please contact the ANA office.

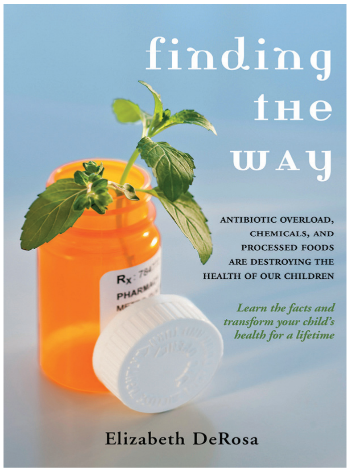
Karla M. Jacobus
President

VOYAGES

Finding My Way Post-Surgically with the Assistance of Holistic/Alternative Practices

BY ELIZABETH DEROSA, WEST CHESTER, PA

My journey into holistic medicine began with my son who was diagnosed with asthma and allergies. As the years passed, my son experienced several other health issues. After years of antibiotics, steroids, inhalers, and nebulizer machines, I finally said, “enough is enough.” I was in search of physical freedom for him and was, unknowingly, preparing for my own future health struggle with a 3.2 cm acoustic neuroma.



I turned to holistic and homeopathic doctors as a last-ditch effort to help my son. It took about a year of re-balancing his digestive system through vitamins, digestive enzymes and other supplements, and a major shift in what he was eating for him to regain his health. I was so astonished by his physical transformation that I wrote and published a book on how we eliminated disease from his daily life.

How does any of this relate to us – individuals who have been diagnosed with an acoustic neuroma? Many of us “AN warriors” suffer daily from physical side effects from the tumor, surgical procedures, and radiation treatments. I firmly believe we can empower ourselves and our family members to take control of our health to

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some degree by becoming educated on both holistic health modalities and western medicine principles to guide us on our journeys.

I believe we can utilize both (integrative medicine) to achieve quality health and healing. Holistic health incorporates the mental, emotional, physical, and spiritual health of an individual. It connects the body, mind, and spirit, or the "whole" of who we are as human beings. I utilized both holistic and modern medicine to assist me with my diagnosis, surgery, and recovery. I know that this complementary approach to my health helped contribute to the foundation of my successful recovery and ongoing healing process.

I will never forget the day that changed my life forever. It was November 5, 2012, when my ENT told me I had a 3.2 cm benign brain tumor. At age forty-one I thought I was going to die! I was suffering from weird symptoms including minor balance issues, ringing in my ear, pressure headaches, and tingling on my right cheek. After much reflection, prayer, and research, I underwent surgery to remove my silent friend. I did, however, have many significant side effects including severe double vision, single-sided deafness, tinnitus, fatigue, and balance issues, but I was extremely grateful to be alive. My biggest, and unforeseen, post-surgery obstacle was ongoing anxiety that left me a shell of the person I was before surgery.

One minute I was laughing, having dinner with my kids, and the next minute I was on the ground, feeling an overwhelming fear that something was terribly wrong. My initial thought was, "After all I have been through and survived, I am going to die on my kitchen floor with my children looking on." Besides having to adjust to the new sensory and physical challenges

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PRACTICES THAT I HAVE INCORPORATED INTO MY LIFE:

- Reduce or eliminate foods that cause inflammation and acidity (acid/alkaline connection). I consume more of a plant-based diet, consisting of fruit, veggies, whole foods (beans, healthy grains, fish, nuts, seeds, and healthy oils), and comfort foods occasionally.
- Use daily vitamin protocol to strengthen my body and nourish my brain. I recommend visiting a nutritionist, homeopathic practitioner, or functional medicine doctor. We are all different and require unique nutritional plans to sustain maximum health.
- Hydrate properly using water, broths, teas, soups, and juice.
- Utilize homeopathic remedies to assist with physical and emotional concerns.
- Enjoy salt and aromatherapy baths.
- Apply Castor oil packs. This practice increases circulation, detoxes the body, and provides support to lymphatic system.
- Take advantage of the many different medical professionals who can enhance the quality of my daily life including neuro-opthamologist for prism glasses, vestibular physical therapist, occupational therapist, MRI scans for re-check, follow-ups with surgery team, and audiologist for hearing aids.
- Take time for myself with exercise, acupuncture, massage, cranial-sacral massage (relieves pressure in back of my head) nutritional counseling, reiki, audiotapes, and educational books.
- Practice meditation, positive affirmations, yoga, and engage in a daily spiritual practice.
- Get the proper amount of sleep each night and nap when needed.
- Reduce chemicals in my daily environment. Read labels!
- Reduce my stress and activity level to a more manageable level for me – I simplified!

MEDICAL REPORT - CSF LEAKS AND SHUNTS

BY MARC S. SCHWARTZ, MD
HOUSE CLINIC, NEUROSURGERY
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Any discussion of CSF leaks and shunts must begin with an understanding of the anatomy and physiology of cerebrospinal fluid (CSF). CSF is clear, colorless fluid which is made by the brain and which bathes and supports the brain and the spinal cord. Most CSF is produced by a part of the brain called the choroid plexus. The choroid plexus consists of several lobes of soft, vascular material which project into the ventricles, or fluid-filled spaces, in the center of the brain. CSF produced within the brain circulates through the fluid-filled spaces within the brain and emerges through several small anatomic passages to the outside of the brain. It then circulates around the brain and spinal cord before being absorbed into the veins running within the dura, which is the membranous layer surrounding the brain.

The main functions of CSF are to cushion the brain, providing physical protection, and to remove metabolic waste made by the brain. About a half liter of CSF is produced per day. This fluid is constantly circulating and being absorbed into the veins. It is also important to understand that this fluid is under pressure; that is, if a hole is created on the outside, CSF will leak out. This is what happens when people undergo spinal taps. CSF pressure is measured and fluid is collected for laboratory analysis.

There are several problems that can occur with CSF related to acoustic neuromas. One problem is hydrocephalus, or build-up of fluid in the brain. Acoustic tumors can cause hydrocephalus in two completely different ways.

First, giant acoustic neuromas can actually distort the brain so much that flow of CSF through the channels of the ventricular system becomes blocked. Fluid then builds up in the center of the brain, causing pressure and neurological deterioration. This type of obstructive hydrocephalus is a medical emergency. In fact, in the past, this was the usual cause of death from acoustic neuromas. Now, the treatment of obstructive hydrocephalus is straightforward. Fluid can be diverted by draining the ventricles directly, using a small, plastic catheter through a small hole drilled in the skull. Fluid can either be diverted temporarily to the outside or permanently through a ventriculoperitoneal shunt. A shunt is a device that drains fluid via a small implanted tube from the ventricles, under the skin, through a valve, and then to the abdominal cavity where it can be absorbed by the body.

The second way that acoustic neuromas can cause hydrocephalus is without a direct obstruction. Even smaller tumors can cause non-obstructive hydrocephalus, which results from clogging of CSF flow at the point at which it is absorbed into the veins surrounding the brain. Acoustic neuromas are thought to shed protein or other material into the CSF, in some cases causing this type of blockage. Because fluid pressure is elevated both within and outside the brain, this is not an emergency situation. It can, however, cause significant neurological problems such as confusion and trouble walking. These are more likely to occur in older patients. Again, ventriculoperitoneal shunting is generally the best treatment.

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that come with having brain surgery, I also had to figure out how to overcome the anxiety that I felt in every fiber of my being.

I realized that I had to put in place practices that helped my son through the years. It was now my turn to take some time for myself and begin to heal on many different levels. Did I think I was going to cure my SSD, double vision, tinnitus, fatigue, or 'wonky' feeling? No, but I realized I could empower myself through alternative practices to help strengthen my body and change my thought process about what I was experiencing.

These days I feel good, although I do have residual surgery side effects. But, my double vision is virtually gone, my anxiety has been greatly reduced, and I have less fatigue and more energy. Sometimes I am able to control the volume of the tinnitus. I am less focused on my challenges and more focused on enjoying life. My vestibular system is in better balance. I now focus less on the ‘wonkiness’. I communicate more effectively and set realistic boundaries for myself, and I feel a greater awareness of my body and what it needs from me on a daily basis to function as best it can.

Tale of Two, *continued from page 1*

hearing loss in my right ear. In the mid-1990’s my primary physician sent me to an ENT who diagnosed the hearing loss as being age-related. I soldiered on, putting my medical issues aside because I didn’t have time to pursue answers. While I worked full-time during the day, I pursued a college degree at night. At last, I graduated in 1999 at age 52. Once I was finished with school, ***I decided it was time to address my medical problems.***

Having gone through this experience twice, once without ANA and once with, we know how important it is to share with those who are facing decisions about treatment.

A CT scan showed a 3.5 x 3 cm mass, confirmed by an MRI. I was told I had a large, benign brain tumor and would have to have surgery immediately. I was definitely scared and did not know where to turn for answers. Nobody “Googled” anything back then. All I heard was “brain surgery”. We didn’t even know what questions to ask. My husband and I gathered our sons and daughters-in-law to give them the grave news. I called my mother and siblings thinking I might never see them again. I was on a lot of prayer lists, which gave me great peace of mind.

Two weeks later, I put my full trust in my neurosurgeon. There was no talk of what type of surgery to have or different approaches. My surgeon opened me up from behind the ear where he found a 4 cm AN and after hours of surgery, I was 90% AN free. But I had not escaped unscathed. Although my facial nerve had been constantly monitored during surgery, I had facial paralysis. I was totally deaf in my right ear. I had no balance. I listed to the right side and needed someone to hold me up. I could not focus my eyes properly to watch TV or read, and my right eye drooped so I could not close it.

After discharge from the hospital, I began intense physical and occupational therapy. I had to retrain my brain so I could walk unattended and write. I had a gold weight implanted in my right eyelid and I underwent physical therapy for my facial nerve. My vision did eventually return somewhat to normal.

After four months, I was able to return to work but I still had to be careful when I walked, consciously adjusting for different surfaces under my feet. At this time, my facial paralysis was very evident. My main concern was that my first grandchild was about to be born and I would never be able to smile at him. I went into a deep depression which lingered for about three months. Finally, I realized that I had a lot of things to be grateful for, and my depression lifted. I retired two years after surgery and became involved in volunteer work which I loved.

My physical condition has improved since then but is not perfect. Besides deafness of my right ear and tinnitus, I still have balance challenges. The right side of my mouth does not close properly. The facial paralysis eventually lessened, but with a cruel twist: synkinesis resulted. This means that when I move my mouth, my right eye closes. This has produced some funny moments. I find that when I smile at people my right eye closes. Often times they think I am winking at them. So naturally, they return the wink. I still avoid mirrors and prefer group pictures. However, I have never shied away from people and I have no trouble getting up in front of a group.

David’s story:

In January 2014, at age 65, I experienced a bad case of vertigo and nausea. I went to the emergency room where a diagnosis of an acoustic neuroma was made, confirmed later by an MRI. Prior to my diagnosis, I had complained of fullness in my left ear. Usually, after taking an antihistamine, the fullness would go away for a while but always returned. My wife kept telling me that I seemed to be losing some of my hearing. I scoffed at the idea. As a retired Air Traffic Controller with thirty-five years on a job that required me to wear a headset, I could blame my lack of hearing on that - if I were to admit to a hearing problem at all. Post-retirement I had begun teaching high school. A few months before my diagnosis, I noticed my students always wanting

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to sit to my left. Later when I quizzed them about this they told me that if they sat on my left side I would not hear them talk to each other. Smart kids! But - I still would not admit to a hearing problem.

After my diagnosis, I researched AN online and found the ANA Support Group in Jacksonville, Florida.

I called Joan Vanderbilt, the Support Group Leader at that time. When I explained that I had just been diagnosed, she commented on how calm I sounded about the whole thing. I explained that we had already been through this when my wife was diagnosed in 2000. What a difference being familiar with the diagnosis made on how I approached my own. I knew that it was not a life-threatening issue. My tumor was smaller than Celeste's 1.3 cm. I had options and time to review them all. I was told that I could wait and see, have radiation treatments, or have surgery.

However, the only person I knew who had an AN was Celeste. Her journey was very complicated with residual problems. That is why our first ANA meeting was so crucial. ***Wow! It was great, helpful beyond our expectations.*** What a blessing it was to see that Celeste was not the norm post-surgery. I breathed a big sigh of relief and decided to have the tumor removed.

In August 2014, Dr. Charles Greene, my otolaryngologist, and Dr. Hanel, my neurosurgeon, performed the surgery, using the translabyrinthine approach. The operation was a complete success. I did not have any facial issues or major balance problems. I did not require any physical therapy. I did lose my hearing in my left ear, experience tinnitus, and when I am tired my left eye droops a bit. I was able to go right back to teaching. After informing my students of the surgery, I was quick to tell them that no one would be sitting on my left side anymore.

Our story:

So, what are the odds that husband and wife would have the same diagnosis? How is it possible that it would strike twice in the same household? We have definitely kept our sense of humor about our unique situation, which is key. We find that if we are at any type of gathering, we make it a point to sit next to each other, deaf ear to deaf ear, so we can hear the people with our good ear. Then, when we get home we tell each other what the other may have missed.

Tremendous strides in acoustic neuroma treatment have been made in the fourteen years between the two diagnoses. There are more treatment options. There is much more information and support available now. We attend ANA Support Group meetings. Having gone through this experience twice, once without ANA and once with, we know how important it is to share with those who are facing decisions about treatment. Not knowing about ANA when Celeste was diagnosed, we are empathetic to those who are newly diagnosed. We also know that we are on opposite ends of the AN experience. At the meetings, people can see how different the outcomes of the surgery can be by virtue of how different ANs can be. There is not a "normal" outcome of any treatment. You just learn to adjust to a new normal. The world does not end with AN, and life goes on.

SPONSOR ARTICLES

Young Mother's Story Has a Happy Ending with Surgery at Vanderbilt

For the past two years, Jordyn Spann's life has been chaotic. A busy mother with four children under the age of 8, she had to cope with her mother's diagnosis of pancreatic cancer and the months of treatment that followed. After her mother died, she broke her ankle. And on top of all that, she was having trouble hearing.

Jordyn's hearing had been slightly muffled off and on for a few years. She had suffered from sinusitis during her pregnancies, and had attributed the hearing problems to severe congestion. "I thought my body was just morphing because of pregnancy; that the sinus and hearing issues would go away." Last May, Jordyn and her husband finally got away to Europe for a much-needed vacation. On the first day of the trip, the right side of her tongue felt like it had been burned. She thought it might be the new toothpaste she had packed, or the stress from the pre-trip planning. When she got home the burning sensation didn't go away. Then one side of her face started feeling numb. Jordyn's primary care physician ordered a CT scan, which revealed a 3 cm tumor. She was referred to a neurologist for treatment. Back at home, she immediately went online and found the Acoustic Neuroma Association website, which offers numerous resources for patients – including a nationwide list of surgeons. She also found two Facebook support groups.


Jordyn and Dr. Rivas

"My mother was treated at Vanderbilt Ingram Cancer Center and we loved her doctor. In my research, I learned that going to a hospital that treats a high volume of cases is important. Vanderbilt treats approximately 120 cases of this rare condition every year." On Facebook, Jordan connected with acoustic

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Acoustic Neuroma Patient Skiing and Hiking after Gamma Knife Treatment

About five months ago, Susan Berman faced a decision she thought she wouldn't need to make for many years. After four years of observation, her acoustic neuroma had suddenly doubled in size and was causing dizziness and other symptoms. The rapid growth of the tumor threatened further impairment if not treated.

Once an acoustic neuroma is causing problems or growing, there are only two options for treatment: surgery or Gamma Knife focused radiation. Her doctor, Stephen Cass, MD, a neurotologist at the Rocky Mountain Gamma Knife Center and a professor at the University of Colorado School of Medicine, recommended Gamma Knife radiosurgery.

Generally, the best candidates for Gamma Knife are patients who have small or medium-sized tumors that are growing, Dr. Cass says. The average age of acoustic neuroma patients he treats with Gamma Knife is 55. Invasive surgery, with its risks of complications, was not the first choice for Berman, who lives in Boulder, Colorado, and enjoys an active outdoor life. She wanted outpatient treatment and fast recovery, which Gamma Knife offered.

Still, Berman needed reassurance. "At one point I really put it to Dr. Cass that I was uncomfortable, fearful," she says. Rocky Mountain Gamma Knife Center was the first Gamma Knife in the Rocky Mountain region and has treated more than 5,000 patients for acoustic neuromas and other brain conditions. Cass has performed well over 200 Gamma Knife treatments for acoustic neuroma. That experience helped reassure Berman.

Gamma Knife is typically a one-time treatment that can't be felt and patients go home the same day. As for the most common fear of

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Dr. Stephen Cass

SPONSOR SPOTLIGHTS

VANDERBILT UNIVERSITY
MEDICAL CENTER

You deserve world-class, personalized care.

Acoustic neuromas are complex conditions, and no two patients have the same needs. At the Vanderbilt Skull Base Center, we have been treating acoustic neuroma patients for more than 40 years. Our patients receive personalized care focused on the best possible outcome with the least invasive treatment.

Expert care for acoustic neuromas at Vanderbilt

Our Skull Base Center is a leading provider of acoustic neuroma surgery. Patients from around the country choose Vanderbilt because of our:

- Decades of experience treating patients with skull base tumors
- Team approach: We perform all acoustic neuroma surgeries as a multi-specialty team that includes fellowship-trained neurosurgeons and neurotologists.
- Dedicated patient care coordinator to personally guide you through your care
- Success rates among the best in the country for key criteria such as facial nerve preservation
- Dedicated intensive care team and neurosurgical ICU: Our nurses and staff are specially trained to care for neurosurgery patients.

For more information about our approach to treatment, including answers to frequently asked questions about acoustic neuroma treatment at Vanderbilt Skull Base Center, visit our web site at www.VanderbiltSkullBase.com. To make an appointment, contact our patient care coordinator directly at (615) 936-4730.

University of Colorado
Anschutz Medical Campus

The University of Colorado Acoustic Neuroma Program is dedicated to providing the most comprehensive and modern treatment for patients with acoustic neuromas. Our multidisciplinary approach offers patients individually tailored care every step of the way. Each patient's case is discussed amongst our board of highly trained specialists to determine the best course of treatment for that patient. We offer all forms of treatment including observation, radiosurgery and all microsurgical approaches. Our state-of-the-art facilities allow our specialists to practice at the forefront of medicine with a focus on hearing preservation and optimal facial nerve outcomes.

If you would like to meet with our providers please contact our program care coordinator, Helen French, at 303-724-2297 for a free review of your records by our specialists and to arrange your appointments. You can also visit our webpage at http://www.ucdenver.edu/academics/colleges/medicalschool/programs/Acoustic-Neuroma/Pages/default.aspx to learn more about our program and each individual provider.

NYU Langone
MEDICAL CENTER

The NYU Langone Medical Center Acoustic Neuroma Team has the largest experience with management of acoustic neuroma and other skull base lesions in the region. The team helps each patient develop a management plan that is customized for each patient's needs. We also have extensive experience with hearing and facial nerve rehabilitation.

Thorough discussions regarding risks and benefits of each management paradigm are encouraged and our advanced imaging team has new paradigms that might help predict nerve location and cochlear involvement thus furthering discussions and predictions about outcomes.

For further information, feel free to contact either John G. Golfinos, MD at 212-263-2950 or J. Thomas Roland, MD at 212-263-5565 or visit us on the web at www.nyulangone.org

ANA FUNDRAISERS

Grazie Mille

A THOUSAND THANKS!

Last month Atlanta Support Group Leader Meredith Daly experimented with a new sort of fundraiser for TEAM ANA.

Meredith and Nick Lotito, invited friends, family, and support group attendees to their home for an Italian-style dinner and fundraising presentation for ANA. After a delicious Italian dinner, guests listened to the hosts speak about the merits of ANA. Before the end of the evening, guests were given the opportunity to make donations.

This special event drew more than 40 people raising nearly $3,000 for patient-focused programs and services. Many guests were unfamiliar with acoustic neuroma but were compelled to donate after the moving presentations. Others already understood what ANA does for patients and that it is necessary to raise money to fund that work.

ANA is grateful to Meredith and Nick as well as each person who attended the event and made a contribution.

If you would be interested in hosting a similar event in your home or community, please contact:

Jennifer Farmer
development@ANAUSA.org
or call 877-200-8211

Fall Walks Raise Funds

TEAM ANA members in New England and Pennsylvania turned out for two Walk4Hearing events. Boston Support Group Leader Nancy Marjollet and Philadelphia Support Group Leader Tracy Perry along with their friends and families each conquered a 5K to increase public awareness of acoustic neuroma and join in support of all who struggle with hearing loss. Thanks to all who participated in raising funds to support ANA.

Raising awareness of acoustic neuroma and funds for patient services is vital and can also be fun and rewarding for you and your friends, family or support group attendees. To find out how you can join TEAM ANA, visit www.ANAUSA.org/team-ana or email Jennifer Farmer at development@ANAUSA.org.

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patients who'd had positive experiences at Vanderbilt. "I called my doctor and told her I wanted to go to Vanderbilt for a second opinion. It's a scary surgery; you want to have the right diagnosis and treatment plan."

"Vanderbilt got me in immediately: I had my MRI on a Saturday night and saw Dr. Rivas on Monday. When you're under that kind of duress you want fast response; you feel like a ticking time bomb when someone tells you you've got a brain tumor."

"I've had such a miraculous recovery! My tumor was pressing on my brain stem and cerebellum, and given its size I knew I could have some lasting facial weakness on that side. I could also lose my hearing in that ear, which did in fact happen. As soon as I woke up from surgery, the numbness in my face was gone. My face shows no signs of nerve damage, an outcome that would have been life altering."

"Today I'm four weeks post-op. I had my follow-up with Dr. Rivas this week; when he saw how well I was doing so he spent the entire appointment telling me not to overdo it. I told him, 'You shouldn't have done such a good job!'"
For more on Jordyn's story, visit www.VanderbiltSkullBase.com.

At 35, ANA Brings Large Number of Participants to Mayo Study

BY MICHAEL J. LINK, MD
PROFESSOR, DEPTS. OF NEUROLOGIC SURGERY AND OTORHINOLARYNGOLOGY, MAYO CLINIC, ROCHESTER, MINNESOTA

It is hard to believe the ANA is already 35 years old! As a patient-run organization offering support and education to patients both at the time of diagnosis, and even potentially years later as they may struggle with ongoing symptoms or disability, the ANA offers a unique and incredible service. Our team at the Mayo Clinic has been intrigued over the years by how variable the severity of symptoms at diagnosis can be, and even more interestingly, how variable the recovery may be following treatment. The same size benign acoustic neuroma may be completely asymptomatic in one patient but create complete unilateral deafness, tinnitus and imbalance in another patient of the same age, sex and race. Similarly, the exact same treatment for the tumor, whether it is radiation or microsurgery, can result in wildly different outcomes; and most importantly, a significantly variable subjective perception by the patient on whether or not the treatment was a success.

Most to the point, there is, not infrequently, a difference in what doctors and patients perceive as the outcome. What we, as physicians, prioritize (facial nerve, degree of tumor resection, hearing) may not be what concerns patients the most (headache, ringing in the ear, dizziness). Over the past few years we have undertaken, along with our colleagues in Bergen, Norway, a large cross-sectional study comparing quality of life, using a large number of questionnaires in AN patients who have undergone surgery, radiation or observation. We've published our results in a variety of the leading peer-reviewed journals and have additional publications in review or press. 1-6

What is the purpose of this study?

The study collects and analyzes ongoing data about how the diagnosis and treatment of an acoustic neuroma affect quality of life and what symptoms or problems most impact quality of life. The goal is to develop recommendations to improve quality of life in people with acoustic neuromas or determine what treatment strategies least negatively impact quality of life.

How do I get started?

Simply email the address below. Please Include your name and mailing address to receive your first survey.

RSTacousticneuromastudy@mayo.edu

Over the past year we have partnered with ANA to get longitudinal data on quality of life. In other words, we already have a very good idea where patients end up with quality of life, and what symptoms bother them most years after treatment or diagnosis, but what we really want to know is what happens from diagnosis through treatment and during follow-up? In conjunction with ANA, we've been able to recruit over 1,000 patients who have agreed to fill out a quality of life questionnaire at annual intervals to help us answer the important question about what happens over time after diagnosis.

The questionnaire takes about 15 minutes to complete, is anonymous, and participants can elect to stop participating at any time. If you are an AN patient, no matter where you are in the process – newly diagnosed or had treatment decades ago – we want to hear about your experience. You can join by emailing us at:

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Congratulations to the ANA on 35 productive and successful years!

1. J Neurosurg. 2015 Apr;122(4):833-42.
2. Laryngoscope. 2015 Jul;125(7):1697-702.
3. Otolaryngol Head Neck Surg. 2015 Aug; 153(2):202-8.
4. Otolaryngol Head Neck Surg. 2014 Dec; 151(6):1028-37.
5. Neurosurgery. 2015 Aug;77(2):218-27; discussion 227.
6. J Neurosurg. 2015 Nov;123(5):1276-86.

ANA MISSION

The mission of ANA is to inform, educate and provide national and local support networks for those affected by acoustic neuromas, and to be an essential resource for healthcare professionals who treat acoustic neuroma patients.

LEGACY SOCIETY

WHY JOIN THE ACOUSTIC NEUROMA LEGACY SOCIETY?

When you remember the Acoustic Neuroma Association through a gift in your will – known as a bequest – you join the Acoustic neuroma Legacy Society, a group of supporters whose generosity has made possible some of our most innovative and effective programs.

There are several advantages of a bequest. It's as simple as inserting a few sentences into your will or living trust and you can change your mind at any time. It may reduce the taxes on your estate. Most of all, you will feel good knowing that your decision is helping others.

To receive more information about bequests, contact ANA today at development@ANAUSA.org. If you have already included ANA in your estate plans, please notify us so that you may be included in the Acoustic Neuroma Legacy Society.

We encourage you to review your options with your tax advisor and/or attorney.

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"Lauren was diagnosed with a 2.5 cm acoustic neuroma and everything changed very quickly. Like many we had never heard of an Acoustic Neuroma and knew nothing about the treatment options and post treatment care.

We decided to make a bequest to the Acoustic Neuroma Association because of the help it gave us and the help it provides to thousands of AN patients and their families. We want to make sure that the Acoustic Neuroma Association is there to support those yet to be identified and that someone will be there to answer the call and provide so many helpful resources when their lives change quickly.

We hope that others will join us and provide a bequest in any amount to the Acoustic Neuroma Association."

Alan and Lauren Goldberg
New York, New York

Skiing, *continued from page 8*

patients, the head frame, Susan says it helped knowing that it would immobilize her head so that the radiation was focused directly on the tumor.

"Because of the shape of my tumor, it only took about a half an hour of being zapped," Susan says. "I didn't feel any of that." As she adjusts to life with the impairments caused by the tumor before treatment, Dr. Cass will monitor the tumor. In the meantime, Susan has returned to most of her previous activities, including skiing and hiking the Rocky Mountains. "I experience occasional nausea or dizziness (impairments from the tumor) when I'm tired or stressed. I continue to work with the loss of hearing," Berman says. "My work is accepting this medical condition. I am a different person than who I was. That takes grieving, accepting and also moving on with all that I'm able to do. I have tremendous gratitude to the medical field and all who helped me with this treatment."

CSF, *continued from page 5*

The next concern is CSF leak, which is a potential complication of acoustic neuroma surgery. While CSF leaks can occur after any brain surgery, they are particularly common after acoustic neuroma surgery. This is because most acoustic neuroma operations involve exposing the tumor via the mastoid bone, which is filled with air spaces which communicate with the middle ear, the eustachian tube, and the nasal cavity. Therefore, there is a potential route of CSF flow through the ear structures and to the nose. Clear fluid dripping from the nose is the most common presentation of CSF leak following acoustic neuroma surgery.

Thus, surgeons performing acoustic neuroma operations must take particular care in closing the skull and incision. Usually, fat or other substances are used to help in creating a seal between the inside of the head and the outside world. CSF leaks are of concern not only because they can cause headaches or other uncomfortable symptoms but also because of the risk of bacteria tracking along the open route and leading to meningitis, which is a life-threatening complication.

There is, however, another factor influencing the risk of CSF leakage. CSF leaks are actually a type "fistula," and two things are necessary for fistulas to occur. First, as detailed above, is the presence of an anatomic weakness or route, and second is fluid pressure. Thus, leakage requires both a hole and also pressure forcing fluid through the hole. Indeed, the higher the pressure, the greater the chance for a fistula to form and to continue leaking — and if fluid is constantly flowing through the fistula, it will not heal on its own. If pressure is high enough, fluid can create new routes of leakage, such as through a skin incision that has not yet fully healed.

Treatment of a CSF leak therefore requires attention to two factors. First, it may be necessary to repair the anatomy of a CSF leak. For leakage through a skin incision this may mean placing more sutures, and for leakage through the nose, this may mean a return to the operating room for re-packing of fat or other measures.

Attention to CSF pressure is also critical. This is particularly an issue since in the days or weeks following acoustic neuroma surgery. CSF pressure is usually elevated compared to normal due to inflammation of the healing process as well as blood and other debris that can be left in the CSF spaces around the brain, clogging the absorption of CSF into the veins. While pressure usually normalizes over time, it is exactly the post-operative period when both pressure is highest and anatomic openings are most vulnerable.

Treatment of temporarily elevated CSF pressure after surgery may be necessary to allow healing of CSF leaks. Again, CSF can be diverted via a drain placed through the skull to the ventricular system. It is usually easier, however, to drain fluid via spinal tap or a lumbar drain placed in the spinal canal at the lower back. Generally, several days of CSF diversion, together with attention to the anatomic reasons for the leak, is sufficient to allow proper healing and closure of the fistula.

In some cases, CSF leaks persist despite the above measures. For instance, normal CSF pressure varies from person to person, and if pressure remains high after a week of external drainage, it may be necessary to place a ventriculoperitoneal shunt in order for a CSF fistula to heal.

After it has done its job of allowing a CSF leak to heal, a shunt may actually not be doing anything of use. In these cases, as long as there are no clinical problems or symptoms, the shunt is typically left in place, since surgery would be required to remove it. As with any implanted device, there is a risk of shunt infection. Shunt infection can lead to meningitis or other serious problems, but, fortunately, this risk is very low after the first few weeks after placement. Any concerns about possible shunt infection should be discussed immediately with a neurosurgeon.

Finally, one ongoing concern is monitoring. As long as a patient with a shunt in place is doing well without symptoms, it is not necessary to routinely do MRIs or other scans. However, most patients with acoustic neuromas will need MRIs for monitoring of the tumor itself (or after tumor removal). Most modern shunts have adjustable valves that can be programmed magnetically. These shunts can be inadvertently re-set by the magnetic field of the MRI machine. Thus, an appointment with the neurosurgeon is often required shortly after any MRI has been done to insure the shunt valve remains at its proper setting.

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Your comments, ideas, suggestions and financial support are needed and welcome.

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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