

P4 MEDICAL REPORT

Acoustic neuroma and trigeminal neuralgia: Is there a causative relationship?
BY JEFFREY BROWN, MD

P11 VOLUNTEERS

Thank you to Agnes Garino and Phyllis Trulock for leading one of ANA's longest standing support groups.

P13 ANA CONTRIBUTORS

Our heartfelt gratitude to those who continue to support ANA through contributions.



NOTES



Q&A WITH SHANNON KAHN, MD

Dr. Kahn is an assistant professor of Radiation Oncology and Director of the Gamma Knife Radiosurgical Center at Emory Saint Joseph's Hospital in Atlanta, GA.

What makes an acoustic neuroma patient a good candidate for radiation treatment?

Radiation therapy is an excellent option in small to moderate sized acoustic neuromas that are not causing pressure with related symptoms on the adjacent

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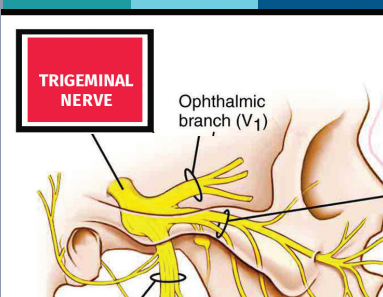


The Start Line: From Brain Surgery to Half-Marathon


BY LEE FALK, BRISTOL, CT

As early as the summer of 2014, I had brushed off symptoms associated with acoustic neuroma as my imagination. Symptoms such as decreased hearing in my right ear, strange numbness in my face, head pain on the right side and slight dizziness. The one thing that I could not ignore was the horrible tinnitus that plagued me for weeks.

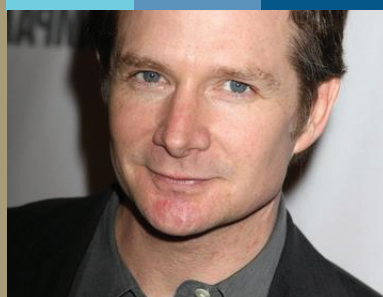
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VOYAGES

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I scheduled a visit to the ENT, which led to a hearing test, then MRI. The diagnosis was a 2.5 cm acoustic neuroma, one that extended into my brainstem. From here, I was referred to another ENT, where my options were discussed. I decided on the “wait and watch” approach: if it grew within the year, I would need surgery.

Leaving the office, it felt like I had a ticking bomb in my head. I have never had surgery in my life—and now I was possibly facing brain surgery. I was in a cloud. I was scared. Suddenly, those imaginary symptoms became real ones, and I started to notice them all the time—so much so that the fear became debilitating. Needless to say, I needed to find a way to cope. That is when I turned to running.

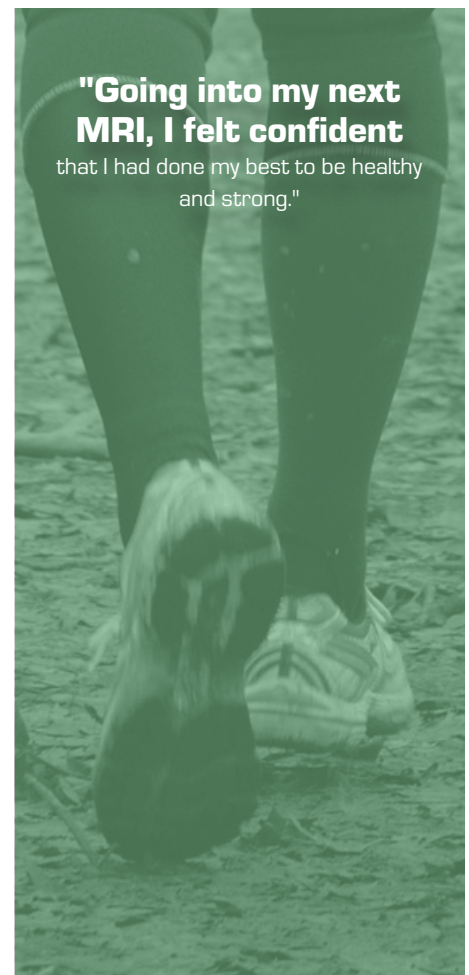
I always loved to run—it was something I did here and there, in between work and other activities for fun or to clear my head. It was a love that turned into a passion, and then to my path to recovery. In my profession as a physical therapist, I knew first hand that the key to a good surgery was being in optimal physical condition prior to surgery. I decided to take my fear and turn it into action. It was the moment I decided to take back my life and not put my life on hold.

What began as occasional runs turned into a well-planned set of weekly goals: three mile runs, two days a week, which turned into five mile runs, three or four days a week. As time passed, I began to enter races, working my way up until I was capable of finishing a half marathon (13.1 miles). But my work didn't stop there. I cross-trained (weights, biking) in order to build muscle strength—I understood that the vestibular nerve was comprised, and put me at risk

for increased dizziness and balance issues. If I could strengthen my core, then perhaps I could reduce the symptoms and have better balance, especially after surgery.

Going into my next MRI, I felt confident that I had done my best to be healthy and strong. When the doctor said there was no growth, I was thrilled. I felt like I had a second chance. I gained a whole year to keep on moving forward. By the next year, 2016, I had run further, farther, faster, as the saying goes. I was certain that, because I didn't have symptoms and felt in optimal shape, that the visit would be quick. Instead, the ENT hit me with the news that the tumor

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"Going into my next MRI, I felt confident

that I had done my best to be healthy and strong."

CEO'S MESSAGE

WE NEED YOU!

PARTICIPATE IN THE ACOUSTIC NEUROMA PATIENT REGISTRY

Acoustic neuromas, also known as vestibular schwannomas, are rare. Because of this, there is a lack of research about them, and the people who have them. Your participation in the AN Registry helps to amplify the voice of acoustic neuroma patients to optimize the search for answers about treatment, causation, and quality of life issues. Creating a shared network that collects experiences directly from patients is an opportunity to build one central and international network of information on acoustic neuroma.

WHAT is a patient registry?

A patient registry is a database of health information that helps describe the patient experience to better inform researchers and the medical community so that improvements can be made to the diagnostic and treatment process. The registry is created by patients who provide answers on the survey.

WHO should participate?

The patient registry is for ALL acoustic neuroma patients. Data from past ANA Patient Surveys will not be included in the registry, so even if you have taken the ANA Survey in the past, we need your participation in the AN Registry.

HOW do I participate?

Go to <https://www.anausa.org/acoustic-neuroma-patient-registry> to read more and to find the link to the AltaVoice website, our partner in creating the registry. Upon completion, you will be able to view the responses of other acoustic neuroma patients (all data is aggregated and deidentified).

HOW will my data be used?

Your data is safeguarded and de-identified which makes it possible to share it with patients, researchers and drug developers working to help find new and better treatments for disease. Another big benefit is that data is shared with patients so you learn how other participants are managing similar health challenges. As a participant you can select whether or not to share your data with medical professionals performing research.

I hope you will join the effort to encourage research studies or speed therapies for acoustic neuroma patients while rapidly increasing our understanding of the issues surrounding acoustic neuromas. By participating in the AN Registry, you can help the whole acoustic neuroma community.



Allison S. Feldman
Chief Executive Officer

ANA would like to thank lead donor **Edward H. Richard and the Edward H. Richard Foundation** for a special grant to fund the promotion and marketing of the Acoustic Neuroma Patient Registry. We are also grateful to the following generous donors who contributed to this effort.

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MEDICAL REPORT – ACOUSTIC NEUROMA AND TRIGEMINAL NEURALGIA: IS THERE A CAUSATIVE RELATIONSHIP?

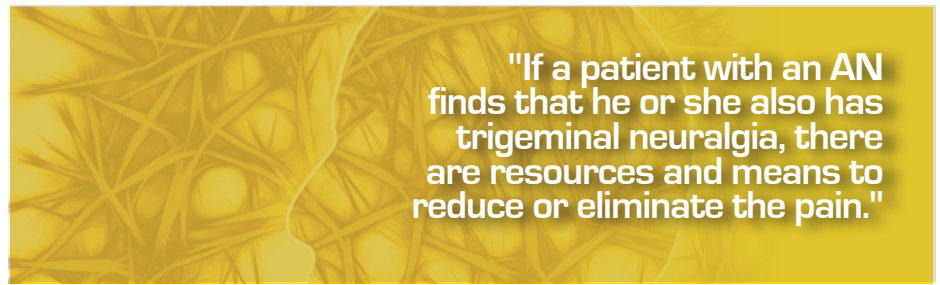


BY JEFFREY BROWN, MD

Dr. Jeffrey Brown, MD is a neurosurgeon with Neurological Surgery PC in Great Neck, NY and the Chairman of the Medical Advisory Board of the Facial Pain Association.

The trigeminal nerve is a cranial nerve with three branches that communicate sensation in the forehead, face and jaw to your brain. Trigeminal neuralgia is condition that patients experience as intermittent, electric shock-like stabs of intense pain in one or more of the branches of the trigeminal nerve. The stabs of pain can be spontaneous or associated with touching the face, chewing or talking. This short article addresses the potential links between an acoustic neuroma (AN) and trigeminal neuralgia (TN). If a patient with an AN finds that he or she also has TN, there are resources and means to reduce or eliminate the pain.

First, the association between an AN and TN is exceedingly rare. Neurologists and neurosurgeons know to image the trigeminal nerve whenever the diagnosis of trigeminal neuralgia is considered. In a series of 1,185 patients who underwent surgery for TN over a period of two decades by Dr. Peter Jannetta, less than 1%, or



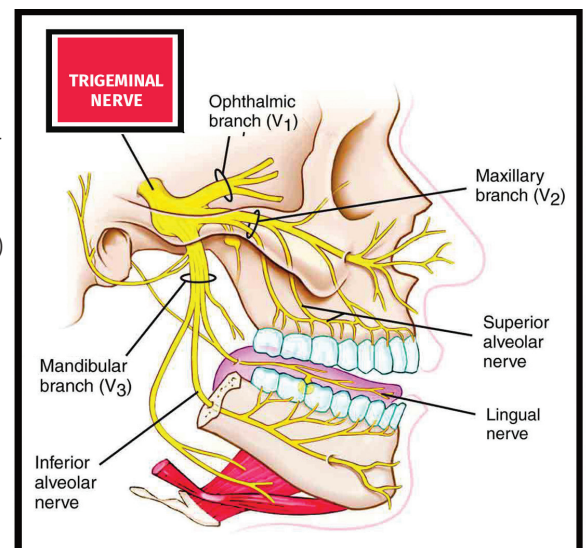
only eight patients had an associated AN. In a series of 2,000 patients over one decade operated on by Dr. John Tew, only four patients had an associated AN. Strangely, in two of those patients the tumor was on the other side of the brain from the pain. Both of the patients in Dr. Tew's series had numbness in their face because of the tumor and one of them had more burning than classical stabbing pain. This is an important observation because it may indicate what treatment is likely to be most effective.

Upon review of his treatment of his eight patients with acoustic neuromas, Dr. Jannetta concluded that the cause of their stabbing facial pain was the presence of an artery that had been pushed towards the trigeminal nerve by the expanding AN. In other words, it was not the tumor that caused the neuropathic facial pain, it was the compression of the nerve by the force of arterial pulsations. The trigeminal nerve is a cable composed up thousands of wires. Biopsies of the nerve done at the time of surgery for the pain from the trigeminal nerve, beneath the site of arterial (or sometimes venous) compression have shown that the insulation surrounding thousands of these nerve fibers that compose the cable that is the trigeminal nerve had been injured. Those tiny "wires" that transmit the sensation of something

touching the face each have their own insulation. When that insulation is repeatedly injured by the mechanical pounding of a blood vessel large enough and close enough to the nerve to cause mechanical damage, short circuits occur. The short circuits happen whenever electricity is transmitted through the nerve indicating that something has touched the face, or there has been movement of the facial muscles. The short circuits are felt as stabs. If severe enough over a long enough period, there can be a constant electrical tingling or burning sensation in the face.

Acoustic neuromas are tumors of the hearing nerve. That nerve, the eighth cranial nerve, is close to the trigeminal nerve, the fifth cranial nerve. Therefore, to cause TN, an AN has had to grow large enough to come in contact with

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had grown. In his words, “It is large, dangerous, and needs to come out.”

Facing brain surgery is not the easiest thing to process. We tend to believe it won't be us, but sometimes it is us. Not because of anything we did or didn't do. And we are forced to face it. During my surgical consult, I was left with an immense number of questions. That's when I turned to the Acoustic Neuroma Association to get answers and help. I directed the same determination to understanding what surgery entailed, for me and my family.

If I were to impart any advice, it would be to make sure to have a surgical team with whom you are confident. Getting a second opinion allowed me to weigh all the facts and determine how they would affect my wellness. Ultimately, I went with the team that best matched my desired outcomes, including running. Feeling I had found my match, I felt a bit of comfort, and then I got back to work—even more determined to get myself into shape before surgery.

I ran a race every week, and even one a few days before surgery. My family joked that I would “run all the way to the operating room.” In addition to running, I got my affairs in order—long and short-term disability, legal matters. I also started listening to positive affirmations to mentally prepare for surgery.

On the day of the surgery, I felt I had done my best to be ready. The surgery lasted six-and-a-half hours. The main artery of the tumor was completely wrapped around my facial nerve, but the surgeon was able to remove the tumor, leaving a tiny piece intact. I lost hearing in one ear, as is common with the translabyrinthine approach.

Upon waking, I had very little

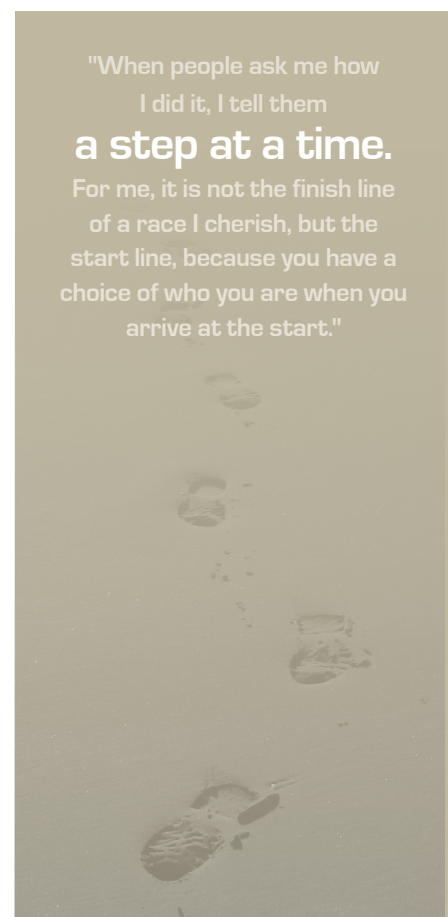
dizziness. While my face was somewhat droopy and my right eye would not close all the way, it was deemed temporary. Basically, all the training I did paid off. Day one in ICU, I rested. On day two, I put my running shoes on, pinned a race bib to my hospital gown, and did laps around the unit. The nurses had to remind me, “It's not a race.”

Once home, I persisted—in fact, my family was amazed that I had the determination to walk every day. By week three, I ran two miles, and five the next. That is when I made the decision to sign up for the Hartford Half Marathon, which fell exactly four months post brain surgery.

It goes without saying that I spent the next few months of recovery time training. But it was more than that: I was beating the odds and taking charge of my welfare. I had not realized how much fear I had been holding onto until after the surgery. I saw life in a new way and realized I had a choice in how I lived it. Would I let life dictate me, or would I actively create a new life, as this new person?

While post-surgery left me with its own set of obstacles—facial weakness, partial deafness, issues with my eye not closing, fatigue—I persevered. Some of my post-surgery accomplishments include completing several races and winning medals for speed in my age group, something I had not done prior to surgery. On the four-month anniversary of my surgery, I stood at the start line of the Hartford Half Marathon, and felt an overwhelming feeling of being truly blessed. That day, I ran my fastest half marathon, proving brain surgery would not slow me down.

Today, ten months after surgery, I am



still healing and adapting to my new life—there is no time limit on recovery. For instance, although it seemed like my eye would never close, it is closing now. I thought I would never smile again, but that came too, though it's different—to go with this new version of me. I have days that I am really tired and have to take a nap. Some days I hate being partially deaf, but on others it is not so bad. I have signed up for a full marathon, among other races.

When people ask me how I did it, I tell them a step at a time. For me, it is not the finish line of a race I cherish, but the start line, because you have a choice of who you are when you arrive at the start. When I get there, I realize just how lucky I am to be alive and starting another journey.

brainstem. Radiation provides an alternative to patients that are either not candidates for a surgical resection or would like to avoid the risks and downtime of a craniotomy.

What are the different kinds of radiation treatment?

Radiation can be delivered using a radiosurgical technique ranging from one to a handful of treatment sessions. This can be delivered with either a Gamma Knife, CyberKnife, or linear accelerator treatment machine. For larger lesions, radiation would need to be delivered more gradually over numerous weeks.

After radiation, what can be expected? Can symptoms arise months after treatment?

Hearing can continue to decline months after treatment in those tumors that are close to the cochlea. Rarely, acoustic neuromas can swell in the first few weeks after treatment, which can last for several months. This can cause a temporary worsening of symptoms that is often reversed with the use of steroids or anti-inflammatory medications.

Does the tumor shrink after treatment?

The goal of radiation is to kill the tumor cells, which prevents future growth. The tumor mass will turn to dead (scar) tissue and will only decrease in size by millimeters over numerous years. Occasionally, the tumor can collapse in on itself, which causes a decrease in size.

There is a history of cancer in my family, should I be concerned about how radiation for AN affects future likelihood of getting cancer?

The radiation dose for acoustic neuromas should remain precisely focused on the tumor with very little radiation to surrounding tissues.

When deciding on treatment, why would a patient choose radiation rather than surgery?

Radiation avoids any the surgical risks involved in a craniotomy. It can also provide an increased chance of hearing preservation in patients with tumors with a few millimeters of separation between the tumor and the adjacent cochlea. And finally, radiation avoids any risk of damage to the facial nerve.

Regardless of family history, the increased risk from the very low dose delivered to healthy tissue should not increase future cancer risk.

Which type of radiation is preferred for hearing preservation? What is the likelihood for regaining hearing after radiation?

If a patient is eligible, I would recommend stereotactic radiotherapy. At our facility this is delivered using the Gamma Knife system, which allows for maximum cochlea sparing for minimization of hearing loss. Unfortunately, hearing will not improve from receiving radiation therapy.

How frequently should MRIs be done as follow-up to radiation treatment?

This is very patient dependent; however, my standard is three months, six months, yearly for three years then every other year.

What is the likelihood for tumor regrowth?

Depending on the size of the tumor, radiation can offer 90-97 percent chance of tumor control.

I have read that the tumor gets 'sticky' after radiation, making any future

surgery difficult or impossible- is this true?

Most surgeons would agree that radiation makes future surgery more difficult, yet still possible. It is rare that the scenario would present for surgery to be needed after radiation. However, in these cases, I would recommend ensuring that an experienced neurosurgeon and otolaryngologist are involved.

We have heard from post-treatment radiation patients who have had facial issues. Can you clarify or cite any studies? If the radiation is not causing the facial issues later down the road, what could it be?

Gamma Knife stereotactic radiosurgery for an acoustic neuroma should not damage the facial nerve if prescribed to the appropriate dose. I would only expect and have only seen this to be due to tumor effect/ invasion or surgical injury.

Which shows better outcomes for maintaining hearing over time, multiple-session therapies or single-fraction radiation? Are there any statistics about this?

There are retrospective studies supporting each side of this debate and it is very possible that a patient can be told conflicting opinions. I am more convinced by the data supporting single-session radiotherapy using Gamma Knife (in the appropriate clinical scenario), as it typically allows for improved sparing of the cochlea, which is the best indicator of hearing preservation.

Is AN treatment using CyberKnife or Gamma Knife relatively simple, or is it worth traveling to a specific center to have it done?

I certainly would support the effort of traveling to an experienced and skilled physician and would describe

stereotactic radiosurgery, whether Gamma knife, CyberKnife or other other modality, as one of the more critical and complex procedures performed in radiation oncology. The procedures require highly trained radiation oncologists, neurosurgeons and physicists.

Is it possible for a dead (necrotized) tumor to become malignant?

There is minimal risk of this occurring. The risk would be quantified as less than one percent.

We are hearing more about Proton Beam treatment for AN. Can you tell us something about it?

Proton therapy continues to be studied to establish whether it provides any benefit over the techniques mentioned above. The physics of protons allows for a steep dose fall off which could

potentially decrease the dose received by surrounding structures. The clinical benefit of this technology remains under debate.

Does radiation effect cognition or memory?

Stereotactic radiosurgery should not.

Will radiation help tinnitus or fullness in the ears?

It typically will not alleviate either of these symptoms.

If the patient is experiencing headache and balance concerns, would radiation alleviate these symptoms?

This is also unlikely. Typically, radiation stabilizes the tumor in order to prevent any worsening of current symptoms and prevention of new symptoms from developing.

If someone already has hearing loss on the tumor side, does the timing of radiation affect retention of the remaining hearing?

The more that the cochlea is able to be spared, the better the chance of hearing preservation. As a general rule, the smaller the tumor, the better we can achieve this goal.

Is radiation for younger patients used more frequently than it was in the past? Why?

Yes, I would agree with this trend. As more patients are treated with longer follow up available, we are understanding and proving the excellent long-term control rates seen with radiosurgery.

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the trigeminal nerve, at least an inch in diameter. Just coming in contact with the nerve may injure it sufficient to cause numbness. However, to cause TN Dr. Jannetta's conclusion was that the tumor must have forced a large artery against the trigeminal nerve.

If open surgery needs to be done to remove or partially remove the AN, and an artery seems to be compressing the trigeminal nerve, a goal of the surgery is to move that artery off of the nerve and maintain that separation with a small cushion. This is exactly the same goal in the standard operation, called a microvascular decompression, that is done to treat TN without also injuring the nerve, even if there had not been a AN or other tumor present.

If someone has TN and an AN can Gamma Knife or Cyber Knife radiosurgery be done?

The usual goal of radiosurgery for an AN is to prevent further tumor

growth. It is not to make the tumor shrink and disappear. So, if the tumor stays the same size, the TN will not resolve. It may be possible to treat the TN with gamma knife if the target is the trigeminal nerve, not the tumor. The problem though is that the nerve is likely to be thinned out by the enlarging tumor making it difficult to visualize with sufficient accuracy to allow targeting with radiation.

If the AN has grown to a size sufficient to cause numbness in the face, and that numbness is bothersome and the cause of a patient's pain, then the nerve should not be injured further by surgery. Otherwise the pain from the additional numbness can get worse. Radiosurgery and other ablative procedures (needle operations that injure the nerve either by gently heating it, bathing it briefly in an alcohol like solution or squeezing it with a balloon) should not be done to treat this constant, usually burning, electrical pain.

A patient that has or had an AN and stabbing facial pain should seek consultation from a neurosurgeon who is experienced and expert in the treatment of neuropathic facial pain using all of the procedures known to be helpful.

As always, treatment decisions in cases such as those discussed above are complex. A patient that has or had an AN and stabbing facial pain should seek consultation from a neurosurgeon who is experienced and expert in the treatment of neuropathic facial pain using all of the procedures known to be helpful. The best treatment is the one that will be selected to cause the least risk of harm. This is requires experience and judgment, not technical skill alone. Additional information about TN is available from the Facial Pain Association at <http://fpa-support.org/>.

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SPONSOR ARTICLE CONFRONT THE ISSUE, COUNT YOUR BLESSINGS . . . AND MOVE ON

When Peter Benson was diagnosed with an acoustic neuroma, it didn't take him long to decide he wanted to have it removed. An actor and musical theater performer who also loves carpentry, Peter says it was his 'carpenter self' who made the decision.

"Monitoring didn't make sense for me," he says, "because I didn't want to be concerned with it growing, and subjecting myself to regular MRIs. It just felt like watching a problem and hoping it didn't get worse. And radiation was out because the carpenter in me trusts the hands-on approach intrinsically. So I was leaning toward a surgical approach from the beginning, and once I met Dr. Selesnick and Dr. Stieg I had no doubt that that was the correct choice for me."

Neurosurgeon Philip Stieg, PhD, MD, and neurotologist Samuel Selesnick, MD, have been working together on acoustic neuroma surgery for 17 years at Weill Cornell Medicine and New York-Presbyterian Hospital, and they have achieved remarkable results with their patients. Their surgical expertise, however, was only part of what persuaded Peter to choose them for his surgery.

"I was deeply impressed from my very first visit with each of these men," he says. "They have very different personalities, but both listen extremely well and possess the easy charisma of being literally among the best in the world at what they do."

The surgery went well and Peter went home from the hospital just a few days later. "I was out of the hospital in three days and taking long walks around the city within days after that," he says. "Two months after surgery I was doing a musical and riding my bike to the theater." He's grateful for having had surgery with a top team.

"It is difficult to speak about Dr. Selesnick and Dr. Stieg without real emotional resonance," Peter says. "They have performed this procedure countless times, but for me this was a singular event. I would like to think that I'm at least a bit improved spiritually. Brain surgery is kind of a big thing and I'm grateful to be healthy and more sympathetic to those who aren't. I truly do appreciate the little



details in my life a bit more, and the people in it way more!"

Peter has some advice for others confronting an acoustic neuroma. Educate yourself and understand your options, get in the best shape possible before surgery, and be brave — "this is so doable," he says. "Hook up with Dr. Selesnick and Dr. Stieg and get yourself connected to Weill Cornell Medicine and NewYork-Presbyterian," he adds. "Then count your blessings and move on."



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SPONSOR SPOTLIGHT WEILL CORNELL MEDICINE ACOUSTIC NEUROMA PROGRAM

The Acoustic Neuroma Program at Weill Cornell Medicine is dedicated to delivering advanced treatments to patients affected by these tumors. The multidisciplinary team, led by neurosurgeon Dr. Philip E. Stieg and neurotologist Dr. Samuel H. Selesnick, offers a wide variety of leading-edge treatment options. The acoustic neuroma specialists

at Weill Cornell Medicine are also expert diagnosticians with access to advanced MRI techniques that allow for earlier diagnosis. Small tumors, diagnosed earlier, are much easier to treat and have better outcomes than those that expand outside the internal auditory canal. Our experts evaluate each patient and recommend the best course of treatment based on a variety of

factors, with the goal of achieving the best possible outcome.

Call Dr. Stieg's office at 212-746-4684 or Dr. Selesnick's office at 646-962-3277, or visit weillcornellbrainandspine.org.

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NEW STUDY: SPEECH AND COMMUNICATION IN PATIENTS WITH FACIAL PARALYSIS

Researchers from the University of Southern California conducting a research study regarding facial paralysis. They are looking for volunteers who suffer from facial paralysis or facial weakness to take a brief, online survey that asks questions regarding your symptoms and how these symptoms affect daily life. This information will help clinicians better understand the specific needs of their facial paralysis patients and guide future clinical decision making.

The goal of this research study is to describe the impact of facial paralysis on oral communication. Surprisingly, there has been little research to date that has measured the effect of facial paralysis or facial weakness on how people verbally communicate. This 10-minute,



anonymous online survey will help doctors and researchers understand

more about the connection between facial paralysis and communication. This study is led by Dr. Jon-Paul Pepper, a facial nerve surgeon at the University of Southern California.

This online survey is completely anonymous and takes about 10-15 minutes to complete. This study has been approved by the Institutional Review Board (IRB #HS-17-00086).

For more information and to complete the online survey, visit the ANAUSA.org website, and look for the Acoustic Neuroma Studies- Learn More button on our home page.

Researchers from the University of Southern California are conducting a research study and are looking for volunteers who suffer from facial paralysis or facial weakness to take a brief, online survey.

LEGACY SOCIETY

ESTATE DONATIONS: REMEMBERING ANA, HELPING OTHERS

When you remember the Acoustic Neuroma Association through a gift in your will – known as a bequest – you join the Acoustic Neuroma Legacy Society. This allows us to recognize you appropriately for your generosity, foresight and dedication to ANA and those we serve.

Your estate plan can be changed at any time. With a bequest, you are not actually making a gift now. You are free free to alter your plans, eliminating the worry that you might make a commitment you could later regret.

If you choose to make a bequest to us, you'll receive valuable tax benefits in addition to feeling good about helping others. Your estate is entitled to an unlimited estate tax deduction for bequests to qualified charitable organizations.

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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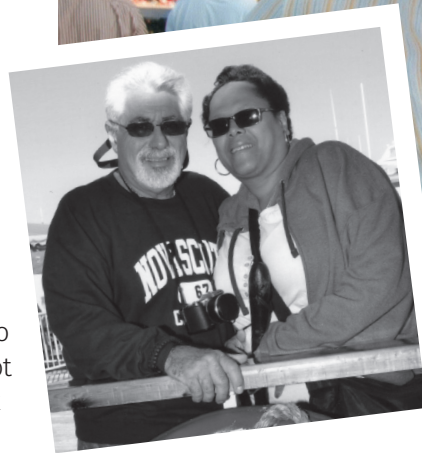
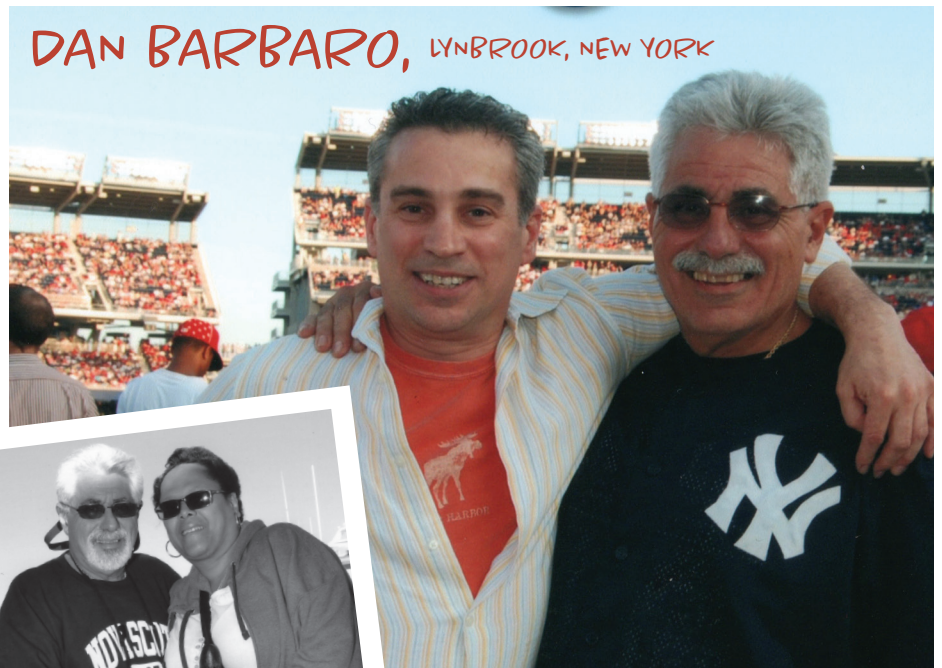
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SPONSOR ARTICLE EIGHT YEARS AND COUNTING

It began with a ringing in the ears. I thought this was a result of many years being around loud machinery working in the construction industry, and artillery and small arms fire when I was in the army and police department. However, the vertigo, occasional nausea, double vision, and ringing in the ears that had started slowly, almost imperceptibly, got steadily worse over a span of six years. The symptoms began impacting my quality of life, and made things that I took for granted either extremely hard or impossible to do. They were making me miserable. I had seen ENTs who first said that it was allergies, but when allergy medications didn't work, diagnosed Meniere's disease and I was put on a regimen of Antivert. This also didn't do much to alleviate the symptoms. It got to the point where I was calling in sick at my job as a Customs Officer at JFK Airport when the vertigo became too severe to allow me to either drive to work, or do the job when I was there.

I scheduled an appointment with a neurologist, who then sent me for an MRI. I got a call from him a couple of days later that I will never forget—the results were in, and he had good news and bad news. "Okay," I said, "give me the bad news first." He told me that all my symptoms were not associated with Meniere's disease, but that I had a type of brain tumor called an acoustic neuroma. To say I was shocked and speechless would be an understatement! After I had caught my breath and collected myself, I asked him after that news, what could possibly be the good news? He said that it was not a malignant tumor, so I had to agree that WAS good news after all.

I chose to go to see Dr. Michael Brisman, a neurosurgeon at



Neurological Surgery P.C. and we went over the options for treatment and surgery. Due to the positioning of the tumor, the doctors did not recommend traditional surgery to remove it. Dr. Brisman and his team explained that the alternative was the Gamma Knife procedure, which would eliminate almost all the severe after effects that could occur with a traditional surgery. After reviewing my options, doing my own research, and considering the pros and cons of the options available to me, I chose Gamma Knife surgery which was performed by Dr. Brisman and Dr. Edward Mullen at South Nassau Communities Hospital in August, 2008.

Dr. Brisman and his team were very caring and had explained each and every step of the procedure. I was very nervous and apprehensive on the day of the surgery, but when all was said and done, it went much better

than I had anticipated. I went home to recuperate with a lot more optimism than I had had for a long time.

I was out of work for approximately three weeks, and by the time I returned, the vertigo and the double vision were almost gone. The ringing in my ear had been reduced considerably. It has been now over eight years since my procedure, and I have been able to resume all the activities that I had been doing before the vertigo and double vision reduced me to a veritable shut in. I am now retired for over three years, and enjoying life again. I see Dr. Michael Brisman for semiannual follow-up MRIs and checkups, and so far, everything is on track. The tumor is dead and stable, and my MRIs are good. I have my life back, and hope to enjoy a long healthy retirement thanks to Dr. Brisman and his team.



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

SPONSOR SPOTLIGHT **ADVANCED TREATMENT**

Neurological Surgery, P.C. is one of the New York City area's premier neurosurgical groups, offering patients the most advanced treatments for acoustic neuromas. Board certified by the American Board of Neurological Surgeons and a Fellow of the American College of Surgeons, Dr. Brisman specializes in the treatment of acoustic neuromas.

At NSPC, we're proud to offer the

latest neurosurgical techniques that provide faster recoveries and better outcomes for our patients. Our expert neurosurgeons are experienced in providing an individualized acoustic neuroma treatment for each patient.

The Long Island Gamma Knife Center offers a noninvasive acoustic neuroma surgery alternative to major open surgery. When radiation or surgery is the best course of treatment, it

has a greater than 95% success rate. NSPC provides compassion combined with knowledge and experience. To make an appointment with Dr. Michael Brisman please call 1-800-775-7784 or visit our website at www.nspc.com.



A GREAT WAY TO CELEBRATE ANA

BY AGNES GARINO AND PHYLLIS TRULOCK, ST. LOUIS SUPPORT GROUP CO-LEADERS

At the meeting of the St. Louis support group in February, patients, caregivers and friends of ANA came together to celebrate. ANA founder, Virginia (Ginny) Fickel Ehr generously spoke to our group via telephone about the beginning days of ANA. We were excited that Ginny could share her reminiscences with us.

We were also pleased that Connie Mahn, 89, one of the co-founders of the group, was able to join us. Also in attendance was recently-retired Dr. Peter Smith, who was the otolaryngologist for many members, and a long-time supporter and member of ANA. We had the opportunity to ask questions of Ginny, Connie and Dr. Smith, who were all so enthused about the importance of ANA for patients and their families. Both Connie and Dr. Smith shared what it was like for AN patients, back when ANA was founded, and how AN treatment has changed over the years.

In addition, we presented thank you certificates to long time group members for their ongoing participation. The afternoon was capped off with lots of conversation, caring and sharing, and some really delicious anniversary cake. The group's ongoing support and enthusiasm about the role and importance of our organization was most evident.

Thank you to Ginny, Connie and Dr. Smith, for being great ANA leaders for all of us.

Thank you to Agnes and Phyllis for leading one of ANA's longest standing support groups. Thank you also to past St. Louis leaders: Donna Anderson,



Ron Bozzay, Pat Callahan, Schatzi Clark, Nita Heinzman, Connie Mahn, Jane Potts, Peggy (Franklin) Wangrow, and Dave Whitfield

CELEBRATING
35
YEARS
ANNIVERSARY

Agnes Garino raised \$5,705 in honor of the 35th anniversary by issuing a challenge gift request to her support group in St. Louis and past and present members of the ANA Board of Directors and Medical Advisory Board.

Thank you
Agnes!



ANA INSPIRED THE "CROOKED SMILE MOVEMENT," LESLIE LOVELACE

My name is Leslie Lovelace and I am a seven-year survivor of an acoustic neuroma. I was diagnosed in February 2009 and had my successful surgery June 25, 2009. I lost hearing in my right ear and have paralysis in my face. It is the paralysis (alterations of my great looks) that has been the most challenging for me. I knew immediately that I wanted to raise money for ANA, but I allowed the challenges with my looks, the many stages of emotions and questions about how to launch my fundraising campaign to keep me from moving forward. Unbelievably, I found myself approaching my 7th year of survival and decided "no more excuses."

I finally stopped focusing on how I wanted things to be and just made a decision about what I would do, but then a stream of sadness fell upon our family with deaths and sickness that almost made me quit. However, I reminded myself no matter how small, I would do

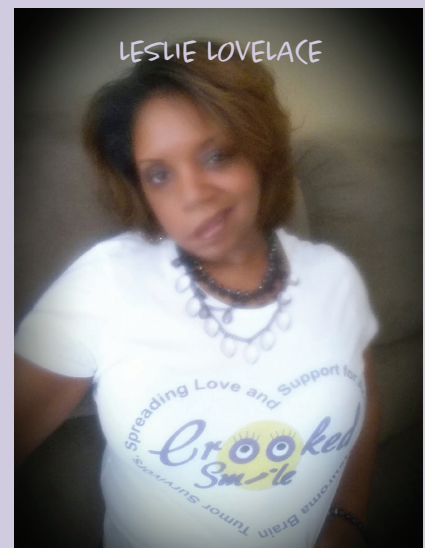


something! I launched a two-month campaign utilizing my Facebook page. Crooked Smile is inspired by my AN Journey I shared through Facebook on my 5th year ANniversary. I asked everyone to post their Crooked Smiles, creating what I called the Crooked Smile Movement. My son created a logo and I decided to sell t-shirts with

a crooked smile. I created small videos journaling my experience weekly to raise awareness of my goals, and held a balloon release to further my fundraising efforts.

The final fundraising tally was \$800! I did not reach my \$2,000 goal, but I was proud that I followed through. The ANA was there for me with resources and support any time I needed them. Truly, without the support I found through them, I might be shut away from the world. I have not allowed my looks (new face) to keep me from living the best life I can, and though my journey has been tough, I've grown and found strength I never knew I had. I am still very hopeful for complete restoration of my face and plan to contribute to the ANA through fundraising.

ANA would like to thank Leslie for sharing her inspiring story and her amazing fundraising efforts!



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ANAWARENESS WEEK



ANAwareness Week May 7-13, 2017

Congratulations! You did it.

The fifth annual ANAwareness Week was a great success because you showed your strength, courage, positivity and heart. You proudly wore your AN Warrior t-shirts, you submitted photos and videos, you shared your stories, you spread the word about acoustic neuroma and you raised funds for ANA's patient-focused education and support programs.

During this year's ANAwareness Week, we aimed to bring you management strategies to help you be your best. Many AN patients credit their happiness and well-being to their focus on improving quality of life by making smart treatment decisions,

finding support, continued AN education, choosing a healthy lifestyle, building stronger relationships, being mindful, staying positive and being your own best advocate for care.

The strides that you take in coping, recovery and well-being give hope to others. Thank you for learning and sharing with the thousands touched by acoustic neuroma.

We are also thankful to our sponsors for ANAwareness Week 2017. Our sponsors are organizations and corporations providing responsible products, devices or services that assist in the diagnosis, education, treatment, management and research of acoustic neuroma.

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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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