

P2 ANA PATIENT EVENT

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P9 THE GREAT BRAIN FREEZE

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NOTES



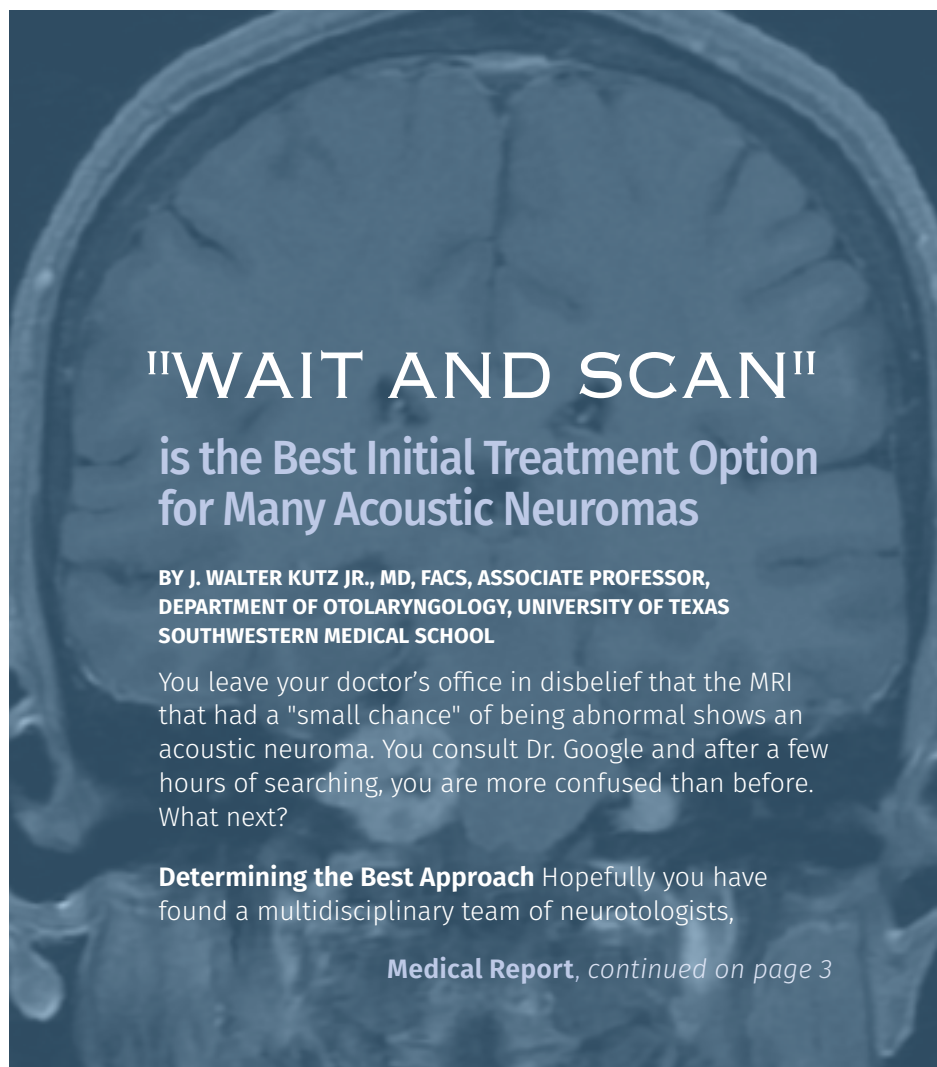
WATCHING, WAITING... AND STILL DANCING

**BY RODNEY DAVIDSON
CAMANO ISLAND, WA
ANA SEATTLE SUPPORT GROUP LEADER**

My balance had always been pretty good. As a dedicated fly fisherman, crossing a raging creek on a fallen log or wading in a swiftly flowing river was a piece of cake. And as a square dancer, I was pretty nimble and coordinated for a 70-year old guy.

Then, in 2013, my friend and I decided to fly fish in the Snake River in Idaho. As I made my way into the river I began staggering around, trying to navigate the underwater rocks. I moved toward a rising trout but stumbled,

Voyages, continued on page 14



"WAIT AND SCAN" is the Best Initial Treatment Option for Many Acoustic Neuromas

**BY J. WALTER KUTZ JR., MD, FACS, ASSOCIATE PROFESSOR,
DEPARTMENT OF OTOLARYNGOLOGY, UNIVERSITY OF TEXAS
SOUTHWESTERN MEDICAL SCHOOL**

You leave your doctor's office in disbelief that the MRI that had a "small chance" of being abnormal shows an acoustic neuroma. You consult Dr. Google and after a few hours of searching, you are more confused than before. What next?

Determining the Best Approach Hopefully you have found a multidisciplinary team of neurotologists,

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CEO'S MESSAGE

ANA Patient Education Event was a Success!

The first one-day ANA Patient Education Event was hosted by the Johns Hopkins Department of Neurosurgery on Saturday, May 12th. ANA Founder Ginny Fickel Ehr welcomed the crowd and spoke about how the common bond of acoustic neuroma brought everyone together for this day of education and making connections.

Dr. Rafael Tamargo spoke about the Johns Hopkins team and introduced the morning panel consisting of Dr. Henry Brem, Dr. Wade Chien, Dr. Tamargo and Dr. John Carey. The panel reviewed acoustic neuroma case studies, and gave mini-lectures on various surgical and radiation treatments. During lunch, attendees had the opportunity to speak one-on-one with the doctors, and chat with one another.

In the afternoon, Jennifer Millar, PT spoke about vestibular rehabilitation and led the group on some simple visual exercises. Dr. Chien and Dr. Carey spoke and answered many questions about hearing restoration and devices, and Dr. Boahene wrapped up the day with a fascinating presentation about facial reanimation techniques.

ANA would like to thank Dr. Tamargo and the team at Johns Hopkins Medicine for a great day of education and AN community-building.

We would also like to thank the following donors for their generous support, allowing ANA to continue to provide these valuable programs:

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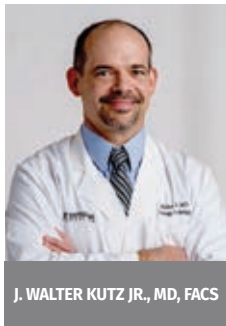
We hope you will join us at our upcoming ANA Patient Education Events! Spots are available for our next event, Saturday, September 29, 2018, hosted by the Vanderbilt University Medical Center Departments of Otolaryngology and Neurosurgery in Nashville, TN. The event is free and open to all. Registration is required.



Allison S. Feldman
Chief Executive Officer

**FOR MORE INFORMATION OR TO REGISTER,
VISIT WWW.ANAUSA.ORG/VANDERBILT OR
CALL STEPHANIE AT 770.205.8211.**





J. WALTER KUTZ JR., MD, FACS

neurosurgeons and radiation oncologists that can guide you through the complex decision-making process. The silver lining is that an acoustic neuroma is a benign, slow-growing tumor. As a matter of fact, recent studies have shown many of these tumors do not grow. A recent study from Denmark authored by Dr. Strangerup and Dr. Caye-Thomasen showed two-thirds of small acoustic neuromas remained stable after ten years of follow up. Another study from Vanderbilt, authored by Dr. Jacob Hunter who is now a neurotologist at UT Southwestern Medical Center, showed only 40% of tumors

grew during the “wait and scan” period. These findings have convinced many acoustic neuroma centers to use the “wait and scan” approach, treating tumors only after growth has been established. At the University of Texas Southwestern Medical Center, we follow about two-thirds of newly diagnosed acoustic neuromas with the “wait and scan” approach.

Not all tumors should be observed, however. Large tumors can cause brainstem compression, hydrocephalus (fluid buildup around the brain) or severe balance disturbance and should be removed with surgery. Smaller tumors in patients who can still utilize their hearing are candidates for hearing preservation surgery

depending on tumor size, tumor location, hearing status, and surgeon and patient preference. If hearing preservation surgery is considered, waiting may not be preferable since hearing could decline during the observation period. Finally, some patients prefer the tumor to be removed over observation for a variety of reasons.

Another management option in treating acoustic neuromas is radiosurgery, which has the advantages of being an outpatient procedure with minimal immediate side effects. The risks of radiosurgery are low and include facial weakness or spasm, facial pain or numbness, hydrocephalus, and very rarely, transformation of the acoustic neuroma into a cancer. The control rate (defined as success in stopping tumor

growth) for radiosurgery is estimated to be around 90%, so only about 10% of patients will require surgical treatment because of continued tumor growth. Since more than half of small tumors do not grow, we only offer surgery and radiosurgery on tumors that have shown growth during the “wait and scan” period.

What You Can Expect in the “Wait and Scan” Approach Once the “wait and scan” approach has been decided between you and your acoustic neuroma team, you will need to have serial MRI scans. We typically recommend the next MRI scan 6-12 months after the initial scan. This will make sure the tumor is not the uncommon rapidly growing tumor. If the tumor is stable, we recommend scans every 12 months. It is important that MRI scans are done as long as the acoustic neuroma is present, since some tumors can grow after a long period of no growth. In many cases, serial MRI scans can be done without IV contrast after the initial study. Patients should discuss this with their acoustic neuroma team.

During the “wait and scan” period, symptoms may worsen, but this does not always

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VOLUNTEER SPOTLIGHT

MY FIRST EXPERIENCE WITH A SUPPORT GROUP

BY JULIE WILSON, ANETWORK VOLUNTEER,
SACRAMENTO, CA



It was one of those perfect weekend days, with the Sierra mountain range vividly outlined against an impossibly blue sky. It was a great day to be outdoors, but I was heading into a supermarket. And I wasn't buying groceries. My spouse and I wended our way past the produce and beyond the snack foods until we reached a series of doors. I opened the one that led to a windowless community conference room. It did not appear to be the greatest place to be on this gorgeous day.

But two hours later, I would emerge

re-energized. I had found in this room a collection of people brought together to share fear and hope, to exchange experiences and ideas, to tell of their highs and lows and to even laugh at themselves. Hey, these were my peeps—those with a diagnosis of an acoustic neuroma and those who came because they love somebody with AN.

This was my first experience at an Acoustic Neuroma Association support group, one of sixty support groups that meet in communities all over the country. I was a relative newbie, seven months out from diagnosis and six months from CyberKnife treatment. I came with lots of questions. What had others experienced post-treatment? What about hearing aids? What local resources could they recommend to improve balance? Oh, I had questions!

But a funny thing happened. I discovered that while people were happy to answer my questions, even a newcomer like me could help others. There were several people that day who had been recently diagnosed. I could see the fear and uncertainty in their faces. When they told their

stories, I could hear how frightened they were of their unknown futures. One person's hands shook as he fumbled with a pencil. Each of them had great spouses—people who had clearly been doing their research—but who also needed to know how to navigate the road ahead.

All of us in the room understood them because we are walking that road, too. Even when there was no clear answer—we are patients and spouses/friends, not doctors or therapists or fortune tellers—listening and supporting can be powerful medicine. I was impressed at that meeting and subsequent ones by the dedication of our leader and others who are years, even decades, out from diagnosis. They may not 'need' to be at the support group, but surely they are needed because they show all of us that AN doesn't put an end to a full life.

If you haven't yet attended an ANA support group in your community, I would urge you to give it a try. I guarantee you will meet strong and giving people. You will learn new things. You will help your AN peers. It will be good for your soul.

INTERVIEW WITH HAZEL BERMAN, ANA SACRAMENTO SUPPORT GROUP LEADER

What prompted you to become a support group leader?

I had been a helper for our group's leader for many years, but when that person stepped down and no one wanted to take on the leader responsibility, I agreed to become the leader because I felt it was so important to continue the group.

Was it difficult to get started?

No – our group had been going for

several years already so maintaining it was relatively easy.

Do you have any tips or best practices for support group leaders?

Bring patience and flexibility to all meetings. The attendees will help determine where the meeting will go – but I always let them talk, ask questions to each other, and make it a real conversation rather than having me lead everything. Of course

there are times when I have to step in to ensure everyone is being heard or to involve those who are quieter. We have a group with a range of procedures and opinions and it's really a great group for sharing and networking.

What has your experience as a patient and running a support group taught you about AN and those who have it?

When most people are diagnosed,

VOLUNTEER SPOTLIGHT



HAZEL BERMAN - SACRAMENTO, CA

they want it fixed right away and want their “normal self” back. Over time, I see that most everyone comes to the realization that healing takes time. And even though it may seem like one can be back to normal in a few months, most agree that it took at least a year to really be better. Universally, all patients (including observation) have agreed that they’ve had to learn patience! The other thing I’ve learned

is that while many of us have common symptoms, we are all very different – whether it is symptoms before diagnosis, personal feelings on doctors, or interpretations of treatment. We have to be respectful of everyone and realize that everyone’s journey is different and personal.

You have been a support group leader since 2006. What’s your secret to being a long-term volunteer and preventing burnout?

I have been doing this a while and I sometimes think it’s time to pass the torch. But I haven’t found anyone willing to take the task on, and I’m too committed to ANA and our group to let it just fizzle... I may not be able to coordinate as many guest speakers as I’d like, or have as many meetings as I’d like, but I’ve learned to just do my best and be available when new patients call or email. Even when we go a long period without a guest speaker, I have realized that the support of one another has been immensely helpful to

our group members.

There are many people with AN who don’t have a support group near them. What advice would you give them if they lack confidence to start their own group or pursue other ANA volunteer opportunities?

Don’t be scared! I’ve found our group attendees to be very warm, receptive, and most of all very appreciative & grateful to have someone ‘lead’ the meetings. The truth is, once the meeting starts and people are talking, there isn’t too much for the leader to do! Sure, I reserve the room, occasionally find a speaker, welcome people and start the meetings... but once the group starts talking, they lead the meetings themselves! I answer questions and if I don’t know the answer, I tell them that I’ll find out. Occasionally, I may have to call a time out and change the direction of a conversation – but that really doesn’t happen often with our group!

Give it a try!

THANK YOU FOR ATTENDING SUPPORT GROUP MEETINGS!

Whether your first meeting or your 50th, your attendance is valuable. Thank you for supporting others with acoustic neuroma and also your leaders who volunteer their time to ensure there are in-person meeting and educational opportunities available.

If you are years post-treatment or perhaps consider your outcome successful - you may not think you need a support group. You may be right. You may not need it, but others do - especially the newly diagnosed person walking into a meeting for the first time. Wouldn’t it be valuable for them to hear your experience and the wisdom you have acquired! If you’ve never attended a meeting, or it has been a while, please consider attending – you can be a wonderful resource to others.

To connect with Julie, Hazel or any of ANA's volunteers, or to get information about volunteer opportunities, contact Melanie at Volunteers@ANAU.SA.org.



signal the acoustic neuroma has grown. Patients with a stable acoustic neuroma can lose their hearing and have progressive imbalance, whereas growing tumors may not present with any new symptoms. Because of the unpredictable nature of an acoustic neuroma, scheduled follow up and MRIs are essential, rather than basing possible acoustic neuroma growth on new symptoms alone.

Patients with an acoustic neuroma should be aware, however, that hearing loss during the “wait and scan” period is possible and can be sudden in about 10% of patients. If you experience a sudden decline in hearing, you should call your acoustic neuroma team. Your team may recommend a trial of oral steroids that can sometimes provide improvement in your hearing. It is generally agreed upon that the better your hearing is at the time of diagnosis of the tumor, the longer your hearing will more likely remain stable.

Facial nerve paralysis is also a concern in patients with an acoustic neuroma; however, it is rare for an acoustic neuroma to cause facial paralysis. Facial paralysis can occur after surgical resection, or less commonly, radiosurgery. Facial nerve paralysis during the “wait and scan” period would be exceedingly rare and would suggest another diagnosis



such as a facial nerve schwannoma.

When Treatment is Recommended

If the tumor is found to enlarge during the “wait and scan” period, treatment will often be recommended. However, in select cases with minimal enlargement, your acoustic neuroma team may recommend a longer observation period to see if the tumor stops growing. Once definite acoustic neuroma growth has been established, your team will recommend surgical removal or radiosurgery of the acoustic neuroma. This decision should be made between you and your multidisciplinary acoustic neuroma team. If the tumor remains small and your hearing is still good, hearing preservation surgery may still be a possibility.

If you do require surgery, a small piece of tumor stuck to the facial nerve may be left behind intentionally to preserve function. In most cases, this small piece of tumor is observed with serial MRIs. If the residual tumor enlarges, radiosurgery is often used to control the growth of the residual tumor. This paradigm of leaving a small amount of tumor behind when stuck to the facial nerve has resulted in better facial nerve outcomes as demonstrated by a recent trial we participated in called the Facial Nerve Outcome and Tumor Control Rate as a Function of Degree of Resection in Treatment of Large Acoustic Neuromas: Preliminary Report of the Acoustic Neuroma Subtotal Resection Study (ANSRS).

For these reasons, the “wait and scan” approach is appropriate and recommended for the majority of patients with small or medium-sized acoustic neuromas. Since growing tumors usually grow only 1-2 mm a year, a short period of observation rarely alters outcomes if surgery or radiosurgery are eventually required. Make sure to ask your acoustic neuroma team if your newly diagnosed tumor can be followed with the “wait and scan” approach.

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

**LAST
CHANCE**

ANA PATIENT EDUCATION EVENT

Hosted by the Vanderbilt University Departments of Otolaryngology and Neurological Surgery

Saturday, September 29, 2018, 8:00 AM - 3:30 PM • Nashville, TN

Presentations will cover a variety of topics for AN patients and caregivers
A limited number of hotel rooms have been blocked at the Courtyard Marriott/
Nashville Vanderbilt West End

For information and to register, visit
<https://www.ANAUSA.org/Vanderbilt>
or call **Stephanie at 770-205-8211**

REGISTER NOW!

ACOUSTIC NEUROMA AND RELATIONSHIPS

DR. SUSAN J. O'GRADY, PH.D.



The impact of such a diagnosis sends shockwaves into every aspect of life. I know this personally, because several months after the Acoustic Neuroma Association (ANA) asked me to write this article, I was—coincidentally—evaluated for symptoms similar to those caused by AN. (In fact, I was diagnosed with the exotic-sounding superior semi-circular canal dehiscence syndrome, or SSCD, which has many of the same auditory symptoms as AN but isn't caused by a tumor).

With a diagnosis of AN, consulting Dr. Google doesn't help. The time between learning you have a brain tumor and beginning treatment can feel like an eternity of sleepless nights, worry, and imagining all kinds of worst-case scenarios. Understandably, we focus on all the negative possibilities that could await us and our family, held hostage by our anxieties.

Hearing loss is the single most distressing part of AN, according to survey research. We are social animals,

so hearing loss can leave people feeling frustrated and isolated from family, friends, and coworkers. Communication problems can leave people feeling less able to participate meaningfully in the world, damaging their self-esteem. Symptoms related to the disrupted vestibular system can also affect daily life, and therefore relationships. Uncertain balance and fluctuating dizziness may require people with AN to interrupt, reduce, or sharply limit activities, even simple ones. Commitments, planned outings, and even simple around-the-house tasks may need to be postponed or canceled, sometimes unexpectedly.

IN SICKNESS AND IN HEALTH

A happy marriage doesn't mean one that never faces difficulty or conflict, although that's probably what most of us imagine when we take our vows. The fact is, most marriages will be confronted with problems, and one of the biggest challenges marriages face is health. The reality of coping with a chronic illness or a difficult diagnosis, such as acoustic neuroma, makes many question or even regret those wedding vows. The promises we make on our wedding day assume a full commitment that requires real inner discipline when faced with a serious and unanticipated health problem.

Another way to look at "in sickness and in health" is this: chronic illness gives us an unparalleled opportunity to remember that acceptance of a common fate is an essential task of marriage. This outlook or process has been called "dyadic coping," in which a couple works together to cope with the stressors that one or both face. A diagnosis is certainly stressful and can feel isolating for both sick and

well partners, each with new burdens to bear. But in a marriage with dyadic coping, the ups and downs of life affect both partners. Sharing the burdens improves health and in turn, the quality of the marriage.

COPING TOGETHER: WE-NESS IN MARRIAGE

So, what does this commitment to facing issues together look like? One clue to how couples see the relationship is their pronouns. These seemingly innocuous parts of our everyday speech give us an important window into the inner workings of relationship. If one member of a couple comes into my office and is talking at his/her partner, using pronouns such as I, me, my, you, and your, this shows a greater sense of independence and distance in relationship. Using words like we, us, and our implies a shared identification between spouses, more intimacy, and more emotional investment in their relationship.

SELF AND PARTNER SOOTHING

We-ness is also associated with more positive and fewer negative feelings, and with lower autonomic nervous system arousal—the fight or flight response. When one partner is anxious or distressed, we can calm them down by using we-ness words. This produces a soothing or emotion-regulating effect on the other spouse. I have seen this many times when counseling couples. For example, when Joyce was becoming agitated about how she would cope with Ben's AN, Ben reached over and gently stroked her arm, saying, "We'll deal with this together." This immediately reduced Joyce's anxiety.

That simple act and kind words can

continued on page 8

make a big difference. We refer to these as emotion-regulating behaviors. Couples can help each other cope with anger, frustration, and fear and minimize the damage on the marriage. In couples therapy, we help partners understand the importance of self-soothing during difficult times, and the value of providing that to their partner when needed.

BENEFIT FINDING: GLORIFYING THE STRUGGLE

When couples come to therapy, I assess their strengths and the areas that need work by asking such questions as “Looking back over the years, what moments stand out as really hard times in your marriage? Why do you think you stayed together? How did you get through these difficult times?” Or, “How would you say your marriage is different from when you first got married?” I am looking for growth as a couple and for a sense of how they cope. Are they a team? Or do they point fingers and accuse their partner of messing things up? Or, one partner may feel powerless to solve a problem and slip into passive endurance, not finger-pointing but not doing anything to rescue the marriage either.

However, some couples find meaning and growth in difficult times. They “glorify the struggle” through a shared narrative that strengthens their bond, giving them a better chance of staying together through hard times. No one asks for a difficult medical problem, but how we react both individually and as a couple will either lessen or increase our suffering. Much of our suffering is a product of our expectations and ideals and holding onto a particular picture or outcome for our marriage. There can be a huge pull to becoming a victim—

either as the person with AN or the martyr spouse.

Jim and Cathy came to couples counseling after they had finished treatment for Cathy’s AN and were left to cope with the changes in their marriage and lifestyle. During Cathy’s diagnosis and for many months afterwards Jim did everything possible to handle the household chores and to give Cathy the emotional support she needed. By the time they came for counseling Jim was depleted and resentful, fearing he was missing out on life. His expectations for their future were bleak. He envisioned

their life would be more about saying ‘no’ to fun and adventure, and that the dreams they formed in their early relationship were gone forever. After all, they had already turned down long-anticipated family events—a wedding, graduation, and a vacation.

Even if we are caught in a difficult situation,

we can find a new perspective, a way to lessen our suffering. Neither Jim and Cathy, nor Ben and Joyce could do much about AN’s impact on their lives, but they could transform their attitudes and find meaning that would convert their pain into compassion for each other. Hope and commitment toward growth as a couple are elevated over disillusionment and a negative perspective.

I do not want to be dismissive of the real, hard problems faced by couples with serious illnesses, or expect them to have a Pollyanna, rose-colored-glasses approach. We can acknowledge the pain and suffering, but at the same time, try to find something in our experience that helps us learn something new, to grow from it.

By viewing the inevitable problems that arise in marriage as “our problems” rather than just one person’s, we strengthen the bond. Moreover, when we work as a team rather than in parallel, we are less likely to complain, criticize, or be defensive. This has a valuable outcome: we naturally reduce each other’s tension, or physiological arousal. When we are relaxed when confronted with problems or conflicts, we are more likely to find ways to manage them—in sickness and in health.

WHAT ARE POSITIVE THINGS YOU CAN DO?

Find good things about your partner. This rewards what they are doing right, and with daily practice becomes ingrained in the brain and will therefore likely continue, reinforcing positive interaction. It is almost magic.

Express appreciation. Say thank you for stopping at the market or for taking out the trash. Even if these tasks arise from a couple’s division of labor, it’s still important to acknowledge them. Pay attention. Listen to the way your partner tells a story about his/her day and respond with sincere interest. Do not rush to change the subject to your own day or allow yourself to become distracted by phones, TV, or other attention snags.

Express affection. Physical affection tends to diminish as a relationship matures, but it doesn’t have to. We know that happy couples give and receive lots of affection through gestures like holding hands, stroking an arm or cheek, winking, and even just smiling. While these may seem obvious and simple actions, they are often absent among couples who come to therapy—not a good sign. Getting back to affection requires letting go a bit, being relaxed, and trusting that your partner will be responsive and not pull back.

THE GREAT BRAIN FREEZE MAKES WAVES

THIS WINTER

Every year, thousands take to icy waters to raise money for charity. Why not make a splash with The Great Brain Freeze?

This winter, challenge friends, family and members of your community to join you in taking a plunge to raise awareness and funds for acoustic neuroma research.

Raising money for a cause that's near and dear to your heart (and brain) has never been more invigorating!

The Great Brain Freeze is a no-brainer!

- Select a date, time and location and notify ANA
- Set your fundraising goal
- Tell your story in an email or social media post, inviting friends, family and community to join you
- Alert the local media
- Stream video from your event using Facebook Live or Instagram

If you aren't brrrrave enough for an arctic swim, host a pool party, ice cream social, popsicle party or slushy soiree, organize a group snowball fight, or any frigid, fun activity. Be creative and make it fun.

To get started planning for The Great Brain Freeze, email development@ANAU.SA.org. We'll help you promote your event and recognize you for your support and your accomplishments on behalf of AN patients worldwide. If you need suggestions to make this a fun-filled event or ways to keep participants warm, we can help with that, too!

Please make sure you and your healthcare provider are comfortable with your participation in this type of

event. If not, please feel free to contact ANA to explore alternative events.



MAKE IT A DAY TO REMEMBER!

- Show your brrrravery by streaming it on Facebook, Instagram or other social media and tag ANA
- Make your day fun. Encourage participants to wear their wackiest costumes and hold a pre-swim parade.
- Invite a local food truck or beverage service to provide coffee, cider, chili or stew to warm up your crowd.
- Take videos and photos to share with ANA and the worldwide AN family.

For more information on how you can join **TEAM ANA** with **The Great Brain Freeze** or another fundraising event, visit ANAU.SA.org/team-ana or email development@ANAU.SA.org.



Earlier this year, two brrrrave ANA members joined friends and family to take the plunge raising nearly \$10,000 for AN research. Emily Truell and friends, Montello, WI and Neil Donnenfeld, Swampscott, MA



Jaspreet Somal, MBBS, FRCA, is a board-certified anesthesiologist with subspecialty training in critical care and neurosurgical anesthesia. He oversees anesthesia care for UC San Diego Health's acoustic neuroma program.

1) How do new techniques in anesthesia help reduce post-operative pain, nausea, and other side effects?

Our AN team includes dedicated, fellowship trained neuroanesthesiologists. We place a strong emphasis on multimodal management of pain and nausea/vomiting, which means that we limit the use of narcotics (also called opioids) and address pain instead by using a variety of other medicines without compromising pain management. Minimizing the opioids reduces the vast number of opioid-related side effects. This surgery has traditionally been associated with high incidence of post-operative nausea and vomiting. We try to minimize this with the use of modern drugs and techniques, and have been very successful in achieving that goal.

2) Having surgery at a high-volume center typically results in shorter operative time and fewer complications. Why is this important?

As we are a high volume program, we have vast experience in providing anesthesia for acoustic neuroma cases. This has helped us to develop and implement procedures most suitable for this specific surgery. It is clear that both perioperative complications and the need for readmission is greatly reduced

when time in the operating room is minimized through the efficiency of our experienced surgical, anesthesia, and nursing teams.

3) How long after surgery will the anesthetic drugs be in my system?

For this surgery, the majority of drugs we use are short-acting, and your body clears them in less than an hour. Because of the nature of the human body, each individual patient reacts uniquely to different drugs. However, scientific studies and our own experience show that patients wake up from anesthesia generally in less than 30 minutes after stopping the drugs, although you may feel drowsy for some time. Generally, it takes a few hours to fully recover from the effects of anesthesia medication. After an uncomplicated procedure, you will be able to see your relatives after a few hours in the post-anesthesia care unit.

4) I am worried that I will wake up during surgery. How am I monitored to make sure this doesn't happen?

We use calculated doses and carefully titrated infusions of sedatives based on your body weight and response to the drugs in use. In addition to the routine monitoring, with the help of neurophysiologists, we monitor the electrical activity of your brain. Combining these modalities, there are statistically astronomically low chances that you will wake up during surgery. However, you might remember waking up from anesthesia, at the end of the surgery, after anesthesia is stopped.

5) Is anesthesia handled differently during a neurosurgical procedure vs a general surgery?

Generally, there are common goals to

all anesthesia such as patient comfort and prevention of awareness. However, there are specific goals to anesthesia for different procedures. Broadly for neurosurgical procedures, we try to maintain your brain blood flow and optimal pressure, monitor your brain and cranial nerve electrical activity and occasionally employ techniques to relax your brain for better surgical access.

7) How can you lower your risk of side effects?

Your care team should provide you with detailed instructions to prepare for surgery including what medications must be omitted just before surgery. One critical component of preparation is obtaining surgical clearance. This can include a physical, blood work and lab work to help determine if you are healthy enough for surgery or if additional testing must be done due to individual risk factors.

Before your surgery, you should discuss your medical history, health habits and lifestyle with your anesthesia team. This information will help us to know how you might react to anesthesia and take steps to lower your risk of side effects. On the day of surgery, you will meet the anesthesiologist or health care professional before heading back into the operative suite. This meeting is also a good time for you to ask additional questions and learn what to expect.

If you have more questions you can visit <https://www.asahq.org/whensecondscount/anesthesia-101/effects-of-anesthesia/> or contact us at 858-657-5376.

UC San Diego Health

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SPONSOR ARTICLE GREAT CARE AT THE HOUSE CLINIC

BY CAMILLE O'LEARY
LOS ANGELES, CA

I almost literally fell into the House Clinic Acoustic Neuroma Center at St. Vincent Medical Center. After a fall at work in which I broke my nose, the doctor at urgent care persuaded me to get a follow-up CT-scan and an MRI. This led to the unexpected finding of the acoustic neuroma.

The ear, nose and throat (ENT) specialist said without hesitation that Dr. Slattery is the guy who can do this surgery. He made the joke "this is your lucky break" and he was so right!

I was a surgery/hospital novice and somewhat skittish of all things medical. Somehow the doctors and staff collectively created a sense of confidence and so I felt very peaceful and at ease in their care. I am a "less is more" person when it comes to knowing specific medical details of what was about to take place. I digested the basics and left it up to the brilliance of the doctors who have the skill to navigate the medical waters. All you really have to do is show up with

clean hair and they do the rest! If you do want to be in the know as to what the surgery entails the doctors are very easy to talk to and they can break things into layman's terms for you.

Dr. Slattery did a beautiful job with the incisions that have given me no pain or problems in the interim. My tinnitus is still there but, it is not as noisy as it was. What a nice bonus!

"Having treated over 350 acoustic neuroma patients last year alone, each patient has a unique acoustic neuroma presentation story," said William Slattery, MD, neurotology surgeon and president of House Ear Clinic. "I consider it a privilege to help patients, like Camille, manage their acoustic neuroma treatment journey."

Dr. Lekovic had a nice way of describing the surgery as a conversation with possibilities of how things could be handled. I also appreciated the painstaking attention he paid to keeping my facial nerve intact; that's dedication, skill and kindness.

St. Vincent Medical Center is a gem

across the street from the House Clinic. Everything is very user friendly and easy to find. The hospital has their own concierge, Roya, who makes sure your concerns are heard. She accommodated a personal medical request from me that made my surgery less overwhelming. The hospital is pristine, clean and private. It was actually very placid and serene.

I have to say surgery was a unique experience; they introduce themselves and welcome you into the surgery room. Everyone had a smile and an upbeat attitude and I was amazed at all the bustle. It was an intriguing look into a world that I had no prior knowledge of. As odd as it sounds, with the intensive, invasive nature of this surgery, I found there really was no true pain afterwards. You may have discomfort from IVs or nausea but no head pain for me, ever!

My only true problem for about two days was nausea. Expect to be a little fuzzy with your thoughts for the first week. It took a few weeks for my eyes to

Sponsor Spotlight, continued on page 14

SPONSOR SPOTLIGHT

According to Margaret Pfeiffer, interim CEO and COO of St. Vincent Medical Center in downtown Los Angeles, the world-renowned House Clinic "attracts some of the best and brightest neurotologists and neurosurgeons in the world, dedicated to the treatment of disorders affecting hearing and balance, including acoustic neuroma and other types of brain tumors.

The clinic has evaluated and treated more than 10,000 patients with benign tumors involving the inner ear and surrounding structures since the early 1960's. "If surgical intervention is needed,"

Pfeiffer, added, "the House Associates partner with our experienced and highly skilled surgical team at St. Vincent to perform the procedure."

Founded in 1943 by Dr. Howard P. House, an ear, nose and throat specialist who later developed a national reputation for his many successful hearing restoration surgeries, The House Clinic now has eight ear specialists on staff. Six of the ear specialists perform ear surgery, one associate specializes in allergic diseases of the ear and one associate specializes in evaluating

**House Clinic
Acoustic Neuroma Center
at St. Vincent Medical Center**

and treating dizzy patients. In addition to the ear specialists there is one associate who specializes in neurosurgery.

Readers interested in learning more about the clinic, its staff and services are urged to visit its detailed web site at www.houseclinic.com.

The clinic is located across the street from St. Vincent Medical Center at 2100 W. 3rd St., Los Angeles, CA 90057. Phone number is (213) 483-9930.

SPONSOR ARTICLE “I’M SO GLAD THE ROOM ISN’T SPINNING ANYMORE”

BY PRESTON BOTTOMY
NEW YORK, NY

At age 38 I felt great – I was living in Manhattan and working as Walmart’s VP for e-commerce. I was active, did Pilates, and had a daily workout regimen to keep me fit. Nobody would ever have guessed I also had a tumor in my head.

My doctors had discovered it seven years earlier after I’d had an accident on the beach. Doctors at the time said it was an acoustic neuroma and told me not to worry about it, to just keep it under observation. I felt fine and didn’t really think much about that little tumor.

Occasionally I would feel lightheaded or dizzy, but I always attributed it to low blood sugar. Then one night at a dinner party I suddenly felt as if the room started spinning. It was unnerving, and it started happening multiple times a day. The uncertainty led me to see a neurologist, who diagnosed me with vertigo. Much to my surprise, she suggested the vertigo could be connected to the acoustic neuroma. She recommended

I see Dr. Philip Stieg, the neurosurgeon-in-chief at New York-Presbyterian/Weill Cornell Medical Center, who has expertise in these tumors.

Dr. Stieg conferred with Dr. Samuel Selesnick, an ear, nose, and throat surgeon who partners with him on acoustic neuroma care, and they agreed that the tumor could be safely removed. I remember Dr. Stieg lamenting that if I had come in when first diagnosed, they could have treated me much more easily. They also warned me that the surgery had risks, including hearing loss in that ear, but I wanted to put a stop to the vertigo so I accepted the risk.

The surgery went well, but at first I couldn’t hear out of my left ear at all, and I could barely get out of bed. Drs. Stieg and Selesnick told me how important it was to get back on my feet, “Once you can walk, you can go home,” they said, and I didn’t want to be a victim of surgery. My dad helped me walk the halls, and the more I walked, the better I felt. I went home two days later, and went back to work



eight days after surgery.

My hearing slowly returned as I recovered, and today it’s not far off from anyone’s day-to-day hearing. I returned to Pilates, and my balance is better now than before surgery. I’m just glad the room doesn’t spin anymore. My experience was fantastic, and I’m glad I went through with the surgery. I made the right choice—it worked out really well for me.

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

SPONSOR SPOTLIGHT

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



Weill Cornell Medicine

Dr. Samuel H. Selesnick
Dr. Philip E. Stieg

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.

VOYAGES - WATCHING, WAITING... AND STILL DANCING *continued from page 1*

falling into the chilly water. After being swept downstream for about ten feet, I regained my footing and looked sheepishly at my friend, who was suppressing a chuckle at my little mis-adventure. Two days later, I noticed a pretty red rock in the shallow water. I bent over to pick it up, lost my balance, and pitched face first into the river. The result was a nice cool bath on a hot day.

After returning from the trip, I was concerned enough to schedule a visit with my GP, who referred me to a neurologist. When he brought up my MRI on the monitor, there was a glowing white circle, about the size of a grape (8 x 7 mm). The diagnosis explained the loss of balance I had been exhibiting. I could still hear out of both ears, and audio tests proved my word recognition in both ears was quite good.

My initial reaction to the AN diagnosis was: "to get that rascal out" of my brain and I was eager to get on with it. The neurotologist told me my AN was considered small, and that I actually had three options. The first was surgery. He felt that the AN could be removed with an 85% chance of preserving my hearing using the middle fossa approach. Other options included radiosurgery and "watch and wait". The decision was mine. I was convinced that I was in good hands and scheduled the surgery for a month later.

After some online research, I joined the Acoustic Neuroma Association (ANA) which sent me some excellent and much-needed information. It was written in plain English the average person could understand.

Another excellent online resource was the ANA Discussion Forum which allowed me to share my concerns and feelings about my newly diagnosed condition. The Forum has many stories from other AN patients who describe their trials and tribulations as



"MY FLY-FISHING DAYS ARE OVER, BUT I CAN STILL SQUARE DANCE THREE OR FOUR TIMES PER WEEK AND ENJOY THE FUN, EXERCISE AND FELLOWSHIP OF THE DANCING."

they grappled with their AN. Many were so supportive of the battle we were all facing, it was very uplifting.

After reading many of the stories on the Forum, and learning more about the possible side effects of surgery, I decided to further explore my options. I liked the fact that radiosurgery would be non-invasive. I decided to cancel my surgery and scheduled radiosurgery instead.

While waiting, I continued researching AN's and also joined the ANA Seattle Support Group. Being able to talk with other people suffering from AN's was extremely valuable.

As the time for my radiosurgery approached, the radiation oncologist indicated that there was some probability that the hearing in my affected ear would be impacted by the radiation due to the close proximity of my cochlea to the AN. Since I still had some hearing in my left ear, I now began to re-evaluate my choice of radiosurgery. Good hearing is essential to square dancing, and I had also been taking physical therapy to deal with my balance issues. The PT had improved it significantly.

About that time, an article appeared in the June, 2014 issue of the ANA Notes newsletter, detailing the results of a study that concluded that taking a daily baby aspirin pill may be effective at inhibiting AN tumor growth so I started on a daily regimen of one baby aspirin.

I took stock of my situation. I still had some hearing, my balance was improving with PT, my MRI's indicated slow or no growth, and I had no other debilitating symptoms. I decided to forego radiosurgery for the time being and move to the "W & W" category, with annual MRI's to monitor tumor growth.

Although I think my balance has very slowly worsened since then, I have been happy with this decision.

My AN grew slightly in 2015 and 2016, but 2017 MRI showed the tumor had decreased substantially from the previous year! My latest MRI in July showed an 18% decrease (by volume) between 2015 and 2018.

Did the baby aspirin regimen cause my AN to decrease by 31% in one year? I don't think anyone knows for certain, but I think others should consider it.

I was also supported by a lot of uplifting prayers from my family and friends, which I believe was also instrumental in the decrease. My fly-fishing days are over, but I can still square dance three or four times per week and enjoy the fun, exercise and fellowship of the dancing.

**FOR INFORMATION ON A NEW STUDY
ON ASPIRIN ON ACOUSTIC NEUROMA/
VESTIBULAR SCHWANNOMA,
VISIT WWW.ANAUSA.ORG AND LOOK FOR
'AN RESEARCH' UNDER THE RESOURCES TAB.**

Sponsor Article, House Clinic, *continued from page 12*

function as a team again and the fuzziness to disappear. I was able to drive my car after three weeks. I bought a few hats for when the surgery was over and I was ready to go in public.

It is important to have a friend or family member to assist you the first week. You have medicine that has to be taken at certain times, and you may be like me and not be able to read the labels yourself. The most basic needs like food prep and

laundry also need to be handled for you.

I am still overwhelmed by the care, support and kindness shown to me by all the staff from the House Clinic and St. Vincent Medical Center.

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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.

Published by the Acoustic Neuroma Association, located in metropolitan Atlanta, four times a year (March, June, September, December).

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