

The

Connection



**A Publication
of the Acoustic
Neuroma
Association of
Canada**

**Association
pour les
Neurinomes
Acoustiques du
Canada**

www.anac.ca

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Spring Edition 2018

President's Message



Welcome to the spring edition of our newsletter - The Connection. There's a spring in my step as I enthusiastically follow in the tracks of our past president and chair, Dr. Rex Banks. Rex capably guided ANAC through the past two years, and we're delighted he's continuing on the board. It was Rex who pointed out our need for an executive director to enhance ANAC's ability to provide useful tools for

those affected by an Acoustic Neuroma (AN). Carole Humphries has worked diligently with the board of directors to expand and improve our newsletter, orchestrate along with Dr. Gelareh Zadeh, ANAC's Scientific Medical Affairs Committee Chair, the very successful 2016 Symposium, and facilitate the creation of our new dynamic website, up and running at www.anac.ca.

Needless to say, the heart and soul of our organization is our members. Without them, we would cease to exist as a charitable organization. One of the most important initiatives we're undertaking this year is to increase support for our volunteer-led chapter meetings. Many of us have benefited greatly from attending these meetings, not only while going through the initial trauma of an AN diagnosis, but also after having completed a treatment. Some continue to attend meetings even years after treatment. Since early 2014, I've been cruising in the *Wait and Scan* mode, yet I rarely miss a Toronto chapter meeting, not just for gleaning information but, far more important, in the hope that my experiences may be of help to those who arrive quivering under the *Sword of Damocles* as they agonize over which treatment path to follow. The support I gained through attending chapter meetings and the highly informative 2016 Symposium made me want to give back to ANAC.

President's Message

Now, I find myself in the role of president and chair of the board, donning three symbolic hats! The first is my *Chair's Hat* -- visualize a massive Sombrero -- under which members of the board of directors combine our varied skills to achieve the common goal of strengthening our association and making it the very best it can be. To see profiles of our leadership team: Chrissie Rejman, Americo Meneguzzi, David Ellison, Nick Kucharew, Rebecca Raghubeer, Dr. Gelareh Zadeh and Carole Humphries, click on the **ABOUT** section at www.anac.ca ...**but don't stop there!**

The second is my *Team Cap* – say, an ANAC blue cap. As a fellow AN patient, I'll continue to share my experiences with other AN patients at chapter meetings and will bring up your questions and concerns at board meetings.

Finally, comes my *Cheerleading Hat* – imagine a colourful, eye-catching beanie. Wearing that, I hope as president to “rally the troops” by encouraging *everyone* in the AN community – patients, their families, ENTs, neurosurgeons and radiologists alike -- to become a Member of ANAC. Your annual fees and generous donations are essential to our survival. Through your official participation, we will have the means to develop a broader network of Chapters across the country, and to build a greater awareness among general practitioners and the community-at-large about this rare skull-based tumour.

Strength comes in numbers: we may be small, but with 100 per cent participation, we can still be mighty. Here's to a strong and successful 2018!

E. Judy Haust

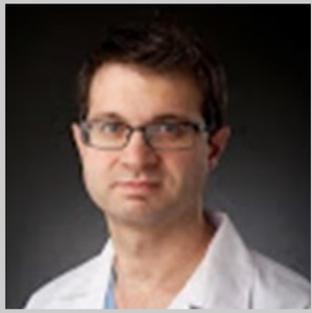
Howard Schultz, an American businessman best known as the chairman of Starbucks offers this wise observation:

"In this ever-changing society, the most powerful and enduring brands are built from the heart. They are real and sustainable. Their foundations are stronger because they are built with the strength of the human spirit, not an ad campaign. The organizations that are lasting are those that are authentic."

What a good reminder that pushing and shoving and trying to make something happen doesn't work and never will. But when we start from our hearts, we not only succeed in business, we succeed in life and leave the earth a better place for having been here.

Salvage Surgery After Radiation Therapy for Acoustic Neuromas

By: *Salvatore Di Maio, MD*



Some of the questions patients with an acoustic neuroma not uncommonly ask are about the issue of salvage surgery after failed radiotherapy: *What happens if the tumour grows despite radiation therapy? Is the tumour harder to remove? What will happen to my facial nerve function?* The pertinence of these questions is reflected in the fact that it is a subject of interest written about in the medical literature and discussed at annual scientific conferences.

As outlined in the **Acoustic Neuroma Clinical Care Pathway** on the new ANAC website, many factors influence the individualized management of a patient with an acoustic neuroma. That being said, many small-to medium-sized tumours for which treatment is recommended can be appropriate for either surgery or radiation therapy.

Many in this situation would argue that there is what is called “clinical equipoise” between surgery and radiation therapy, meaning one option has not been adequately shown to be better or inferior to the other. Beyond physician measured outcomes of tumour recurrence, hearing, facial function, etc., several studies have shown that the quality of life in acoustic neuroma patients who undergo either surgery or radiation therapy is very similar. In many cases the decision to pursue radiation therapy over surgery can come down to patient preference.

The principle goal of radiation therapy is referred to as “tumour control” which means either an arrest of tumour growth or actual tumour shrinkage. When calculating treatment failure after radiation therapy, it is important to discriminate from transient increases in tumour size which can be part of the radiation response and is termed “pseudoprogression.” This occurs ~20% of the time and generally between 6-24 months following radiotherapy. In most of these cases, the tumor enlargement is self-limited and either stabilizes or the tumour subsequently shrinks. Although the mechanism by which this occurs is not completely understood, it rarely represents a situation of uncontrolled growth requiring salvage treatment.

In high volume centers of excellence with published long-term results, the proportion of patients with acoustic neuromas who truly fail radiation therapy necessitating “salvage surgery” is typically well under 10% and probably closer to 5%. One should account for several factors when interpreting this data, the most important being the size (specifically the volume) of tumour being irradiated. Other variables include the rate of tumour growth prior to radiation (if growing at all), and the type and dose of radiation being delivered. Nevertheless, the majority of patients with acoustic neuromas that were deemed appropriate for radiotherapy will achieve tumour control. But in the unlikely event that radiotherapy fails, what then?

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To date there are a few published studies of salvage surgery for previously irradiated acoustic neuromas. The timing of tumour recurrence after radiotherapy was very variable and occurred at any time, including after a period of long term (>5 to 10 year) stability. Observations noted at the time of surgery for post-radiation tumours include increased scarring at the interface between the tumour and the facial nerve, increased irritability of the facial nerve during dissection and a firmer tumour consistency. The extent of resection is more likely to be incomplete compared to series of sporadic (i.e. not previously irradiated) cases, in part due to the practice of some surgeons to purposely not aim for a complete resection. The results of post-operative facial nerve function are difficult to interpret because of variability in individual surgeon expertise, however a general relationship between attempts to achieve a gross total resection and more severe post-operative facial nerve dysfunction can be appreciated. Interestingly, a consistent finding is that the rate of recurrence in cases with incomplete resection is very low. For example, in one series of 73 patients with previously irradiated acoustic neuromas, there were no recurrences in those patients who underwent incomplete resection after a mean of 5.7 years of follow-up.

My personal experience is that previously irradiated tumours are heterogenous in consistency, with some areas of tumour looking very typical (i.e. virgin) without significant scarring and can be removed much like non-irradiated tumours. In other areas, the tumour is more firm or fused to the surrounding tissues, including sometimes to the facial nerve or brainstem. As a result, completely removing a previously irradiated tumour can be more challenging.

Many surgeons (including myself) will rely very heavily on intra-operative monitoring of the facial nerve. This refers to placing electrodes at the time of surgery to measure the reaction of the facial muscles to stimulation over the course of the operation. Several techniques for stimulating and monitoring the facial nerve are possible and some allow verification of *function* of the nerve and not just irritability or anatomic continuity of the nerve, neither of which are particularly accurate in predicting post-operative facial nerve function. Facial nerve monitoring is especially useful to me in previously irradiated acoustic neuromas, where the usual visual or tactile “cues” the surgeon uses to safely dissect around the facial nerve are disrupted. If the facial nerve monitoring reaches a specific threshold beyond which post-operative facial weakness is likely, then I am likely to stop removing the tumour and leave a small residual if necessary. As mentioned above, we have relatively good data that shows that even if a small volume of tumour is left behind, it is likely not to grow, and by proceeding based on the intra-operative monitoring data, the patients’ facial nerve function can be preserved.

In summary, radiotherapy is a very reasonable option for many small-to medium-sized acoustic neuromas, and most patients who need to undergo treatment will have good results. Tumour

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growth after radiotherapy is generally uncommon. Surgical resection of previously irradiated acoustic neuromas is more challenging as described above. Besides surgeon experience and expertise, intra-operative monitoring of the facial nerve is an important adjunct to ensure maximal safe resection. Leaving some tumour along the facial nerve probably occurs more frequently compared to non-irradiated cases; however, most studies concur that the residual tumour is unlikely to recur. When patients ask me about salvage surgery in the event radiotherapy doesn't work, and despite the challenges described above, I respond that most people will still do well in that scenario and I would not worry about that when deciding which upfront treatment to pursue.

Salvatore Di Maio is a skull base neurosurgeon and assistant professor at the Jewish General Hospital in Montreal, Quebec. He attended medical school at McGill University and completed his neurosurgical training at the University of British Columbia. He also received in-residency training in endoscopic skull base surgery under Paolo Cappabianca in Naples, Italy, and a clinical fellowship in skull base and cerebrovascular surgery with Dr. Laligam Sekhar at the University of Washington in Seattle, USA.

Dr. Di Maio specializes in open and minimally invasive procedures for skull base tumours, meningiomas, acoustic neuromas, pituitary tumours, and neuro-oncology.

A Tip: Possible Tinnitus Trigger

By: Evalyn Hrybko

I want to share something I learned from Nerissa Davies, MSc, RAUD, RHIP Registered Audiologist at the AN gathering in Courtney, BC.

It is 48 years since my AN surgery, and I have been a part of many AN gatherings over the years. Nerissa shared that for some individuals with an AN, who experience tinnitus, tomatoes can trigger an attack of tinnitus. So, on purpose, I had a sandwich with two slices of tomato. Guess what? Lo and behold in the morning, in fact, all day long, the buzzing was quite bad. I usually stay away from tomatoes because I have acid reflux, but I wanted to check this out for myself. Wow! I am now wondering if acidic foods in general may be a factor. I learned some years ago that salty foods, coffee and ASA in aspirin, can contribute to tinnitus and that those with Meniere's disease, must also be careful to assess these possible triggers.

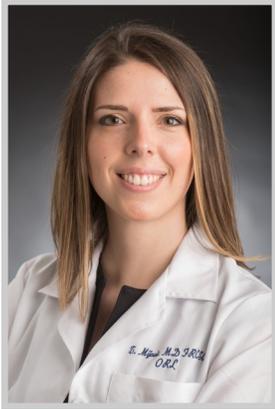
Popular performer Willie Nelson shared this personal experience:

"When I started counting my blessings, my whole life turned around."

Notice he didn't say when he made a lot of money or when he wrote a hit song or performed in front of thousands of fans. He started counting his blessings and everything changed.

Understanding Vertigo in Vestibular Schwannomas

By: Tamara Mijovic, MD



A Quality of Life Issue

The cardinal symptoms of vestibular schwannoma are unilateral hearing loss, tinnitus, vertigo and unsteadiness. Most patients present with unilateral hearing loss (94%) and tinnitus (83%). Vestibular symptoms such as spinning vertigo, nausea, disequilibrium and imbalance have often been reported as mild, but are nevertheless present in 40 to 75% of patients. There is however remarkable variability in vertigo symptom severity and impact among patients. Several factors could explain this variability including the size of the tumour, the rate of growth, the rate of vestibular loss and the patients' overall premorbid functioning level.

Recent studies focusing on quality of life associated with vestibular schwannoma have shown that when present, vertigo is the most debilitating and distressing symptom with respect to health-related quality of life. It also constitutes a risk factor for future work disability. While the subjective extent of impairment by vertigo is quite low initially, it could change considerably after intervention (surgery or radiation).

Why is there vertigo?

As humans, we orient ourselves in space with the input of our senses (vision, proprioception and vestibular function) integrated at the level of our central nervous system. The differential diagnosis of dizziness is therefore very broad.

The general complaint of «dizziness» is divided into four subtypes with different underlying etiologies: vertigo, disequilibrium, presyncope and psychological dizziness. Vertigo is a false sensation of movement of oneself or the environment. Disequilibrium is a sense of postural imbalance associated with a loss of balance that can relate to issues with the musculoskeletal system and proprioception. Presyncope is a feeling of faintness while psychological dizziness is typically related to anxiety or mood disorders. Vertigo can originate from a peripheral or central unilateral, asymmetric impairment of the vestibular system that causes an illusory sensation of movement.

The peripheral vestibular apparatus includes three semicircular canals, the utricle, saccule and the vestibular nerves. The central vestibular system comprises the vestibular nuclei, the brainstem, spinal cord, vestibular cortex and the cerebellum.

The role of the vestibular system is to help us maintain stable vision when the head is moving (through the vestibuloocular reflex (VOR)) and to contribute to maintaining posture (through the

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vestibulospinal (VSR) and vestibulocolic reflexes (VCR)).

In the context of vestibular schwannoma, the tumour growth on one of the vestibular nerves affects the function of that nerve thus generating the asymmetry. It means that the vestibular reflexes (VOR, VSR and VCR) are impaired. Although acute changes of vestibular function can occur with vestibular schwannoma thus generating vertigo attacks with nausea, vomiting, lateropulsion to the lesioned side, and nystagmus to the contralesional side, the clear majority evolve so slowly that the changes of vestibular function are very subtle, and most patients do not experience severe attacks of vertigo. Vertigo is the presenting symptoms of only 10-15% of all vestibular schwannoma. More commonly, the patients with vestibular schwannoma might report symptoms of blurry vision for a split second when moving their head quickly toward the side of the lesion which is a sign of impaired VOR. They can also report a vague sense of imbalance and dizziness. Reports suggests that up to 75% of patients with vestibular schwannoma have some degree of vestibular symptoms.

As the tumor grows, it can put pressure on the brainstem and cerebellum thus generating more significant symptoms of dizziness and balance problems.

How does the approach to the management of vestibular schwannoma impact on vertigo?

The three commonly accepted treatment modalities for vestibular schwannoma include radiation therapy, microsurgery and observation. Most studies comparing the different treatment approaches focus on comparing neurologic morbidity, hearing preservation and facial nerve function outcomes, all of which can be objectively assessed. Given that vertigo and dizziness are very subjective symptoms, the impact of treatment modalities on vertigo control is much more difficult to assess. A variety of scales and questionnaires have been designed to assess the extent and impact of vertigo (Dizziness Handicap Inventory (DHI), Vertigo Symptoms Scale (VSS), Short Form 36 Survey, Glasgow Benefit Inventory, etc.). None of these assessment tools is perfect as they all have their advantages and limitations. At the present time, while there is significant heterogeneity among small studies, there are no large-scale studies assessing vertigo symptoms systematically. It is therefore difficult to draw firm conclusions as to the impact of various treatment modalities on vertigo symptoms.

Smaller quality-of-life studies seem to suggest that surgery is associated with an increase in impairment of QOL by vertigo in the post-operative period. One study has shown that 31% of patients have disequilibrium lasting > 3 months after surgical removal of an acoustic neuroma. Worse outcomes were associated with age > 55.5 years, female gender, constant preoperative disequilibrium present for > 3.5 months, and central findings on electronystagmography.

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Depending on the surgical approach, post-operative dizziness could be related to the extent of cerebellar retraction (retrosigmoid approach), and the loss of any residual vestibular function spared by the schwannoma. Because this change happens acutely at the time of surgery, vertigo is more readily perceived by the patient. Pre-operative vestibular function does impact the perceived dizziness after surgery. Therefore, someone who has had a slowly growing acoustic neuroma on one vestibular nerve and then has undergone surgical removal of the neuroma may exhibit almost no vestibular symptoms because the progressive and complete vestibular loss has already been compensated for progressively as the neuroma grew. By the time the surgery takes place, the patient has no effective vestibular function in the affected ear and the surgery could not worsen it further.

Because there is heterogeneity in the extent of vestibular function pre-operatively, there is a lot of variability among patients' postoperative dizziness symptoms. Conversely, radiation therapy seems to be associated with lower rates of vestibular symptoms in the acute post-treatment period. Given that the impact of radiation can be felt for years after the treatment, some studies suggest an increase in dizziness in the years after treatment.

Treatment of Vertigo: What is vestibular physiotherapy and how does it work?

Regardless of the treatment approach to vestibular schwannoma, significant vertigo symptoms can be present and impact the patients' quality of life. Specifically targeting these vertigo symptoms and overall balance is an important component of the care provided to patients with vestibular schwannoma. Given that regaining vestibular function on the tumor side is not possible, the therapeutic approach focuses mainly on optimizing compensation for this unilateral vestibular loss through vestibular physiotherapy.

Both animal and human studies emphasize the importance of early ambulation with head and neck mobilization in the first four post-operative days. Mobilization in this crucial period of recovery has a significant impact on the course of vestibular compensation. Encouragement and reassurance is needed at that time since patients might feel quite dizzy during this acute post-operative period and be very reluctant to move. Antiemetics and vestibular suppressants can be used to control the nausea in this acute setting but should not be used long term as they hinder the compensation process.

Vestibular compensation encompasses a variety of centrally mediated mechanisms that help us achieve vision and postural control despite the lack of vestibular input. At the level of the brainstem and cerebellum, the activity of the vestibular nuclei is modulated but the impact on maintaining the vestibular reflexes is marginal. Compensation happens mainly through input substitution and learned anticipatory adjustments which can be trained.

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The loss of vestibular function from one ear leads to increased reliance on vision and somatosensory information to perceive self-motion, orient the body, stabilize the head and control the center of mass. For instance, instead of the VOR, vision is stabilized through anticipated covert eye movements (saccades) that happen during the head movement.

Through a variety of exercises centered on stabilizing vision and maintaining balance while the head is moving, and the body is in motion, vestibular physiotherapy triggers the development of these alternative compensatory mechanisms. In the initial postoperative period, these exercises can feel as if they trigger the vertiginous symptoms because they bring out the vestibular deficit. This is the stimulus necessary for the brain to engage the compensatory mechanisms. With time and effort, desensitization to the symptoms and compensation occur while a more robust balance is achieved, all contributing to decreased vertigo and disequilibrium.

Dr Tamara Mijovic MD CM FRCSC is an assistant professor of Otolaryngology-Head and Neck Surgery at McGill University. As a fellowship trained Otologist and Neurotologist, she is the director of the McGill University Health Center (MUHC) Vestibular Laboratory and an active lateral skull base surgeon part of the multidisciplinary Skull Base Surgery Team at the Jewish General Hospital.

Our Chapter Network—Where REAL conversation happens... Reassuring, Educational, All-inclusive, Lively!

The Acoustic Neuroma Association of Canada is working to develop support groups in each province across Canada to ensure people affected by Acoustic Neuroma receive the support they need. Volunteers are currently needed in British Columbia, Quebec and all East Coast Provinces.

If you are interested in helping establish a new group in an underserved area, please contact Carole Humphries at the National Office for an information package and support.

director@anac.ca

1-800-561-2622

Rick Warren, author and speaker known as a voice of wisdom, hope, and encouragement:

"The battle for your life is in your mind."

Strong words, simply stated, remind us that the challenge and difficulties we face in life start with our thoughts. How is your thinking today influencing the choices you make that lead to the actions you take and the beliefs you cultivate?

My Acoustic Neuroma Journal

By: Marilyn Sharples, North Vancouver, BC

(An edited version of my shared experience to the AN BC Chapter Meeting October 21, 2017)



Reflecting on the last eighteen years of my life, I go back to the beginning of my journey. In 1999, I was studying ASL, American Sign Language, and Deaf Culture at college. It was a life long dream to be able to converse fluently with the deaf. I had grown up with a deaf brother and we had only communicated using drawings for fifty-five years.

Nearing the end of the spring term, I experienced balance issues, fatigue, nausea, dizziness, ear ringing, diminished hearing and a feeling of fullness in my left ear, room spinning and trouble walking without support. I wrestled with questions and especially “FEAR”- fear of the unknown. I needed answers!

I was diagnosed with benign positional vertigo (BPV) because of acute labyrinthitis by Dr. Michael Smith, ENT in North Vancouver. I went to a Balance and Dizziness Disorder (BADD) meeting to learn coping skills. I was still dizzy. Back to Dr. Smith. He arranged a Cat Scan immediately and found my little friend – a 1.5 cm. diameter mass in the left cerebellopontine angle, that contains cerebrospinal fluid, arachnoid tissue, cranial nerves, and associated vessels, which is consistent with an Acoustic Neuroma. Now I could plan!!

I met with Dr. Michael Boyd who outlined three options considering my symptoms:

1. Wait and Scan: As my tumour was small, a follow-up MRI would be done one year later.
2. Surgery: I still had functional hearing in my left ear. Prior to surgery, I would need a full examination of the brain stem evoked potentials and full audiogram assessment including speech discrimination to give a better estimation of possible hearing salvage. Dr. Boyd quoted me a 50-50 chance with the posterior fossa approach. He felt the tumor was not ideal for a middle fossa approach as my tumor went to the apex of the canal. In such circumstances, hearing is a bit more difficult to preserve. Nevertheless, he thought removing the tumor was a viable option.
3. Stereotactic radiation: This option offered an advantage of a decreased risk of hearing loss and facial nerve injury, However, not zero. He felt because of my age the potential for delayed effects from stereotactic radiation was less of an issue. He felt this was a reasonable alternative.

None of these alternatives would alter my balance. In fact, surgical intervention would likely make it transiently worse because of the loss of any residual vestibular nerve function.

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However, Dr. Boyd felt I would gradually compensate and my dizziness and balance would improve with time with any of the treatment options.

Dr. Boyd handed me a ANAC pamphlet and sent us on our way. I needed to reach out to Evalyn Hrybko, ANAC Chapter Leader who kindly identified others to connect with. Everyone had a story and filled me with valuable information. My husband and I attended meetings and met wonderful caring and concerned people. I was no longer alone.

Because my husband is a journalist, we commenced research at the kitchen table. We poured through material on stereotactic radiation, fractionated versus one shot. We read everything about machines, LINAC, Gamma Knife, Cyber Knife, and the Lars Leksell frame. We became more and more confused. We called hospitals all over America. Our scribbler was filled with names and places (Toronto, Pennsylvania, Alabama, Cleveland, Rhode Island, California, and Washington). Could we afford to go to the States for treatment? Was the Gamma Knife indeed better? So many questions.

We were relentless in our search to do the right thing. We contacted a neighbour who studied at Stanford and was a Director of Engineering Physics, Associate Professor and Biophysics Associate at UBC and Director of the Michael Smith Lab Platform and Genome BC Technology Development Platform. Dr. Marziali came right to our kitchen table. He reviewed all our research and simply said that the LINAC was a good machine. He had worked with it and assured us that the LINAC pinpointed with the same accuracy as the Gamma Knife. He also felt the fractionated approach with the LINAC gave the healthy tissue more chance of recovery between treatments.

I was on my way.... I met with Dr. Michael McKenzie, radiation oncologist, at Vancouver Cancer Clinic who advised me that I was a candidate for stereotactic fractionated treatment on the LINAC 2 machine. We accepted the rationale that this treatment would result in the highest killing of tumor cells with the lowest effect on normal brain cells. There also would be less risk to the facial nerve, and importantly, a high probability of preservation of my hearing. The treatment itself would involve twenty-five visits over six to seven weeks.

A subsequent MRI indicated my tumour measured 1.7 cm. which included the tail. As my appointment did not come up for eight months. I busied myself with a night school course in Advanced ASL. I walked everyday, had massages, avoided salt and never looked up. We attended ANAC chapter meetings. By mid-May, the dizziness was back with a vengeance.

July 2000 found me in the "Mould Room" for the 45-minute mask construction. The technicians built a mouth prosthesis to hold my external mask firmly in place during my treatments. The mask itself consists of a Delrin kind of meshed plastic. A rectangular piece was heated and then

My Acoustic Neuroma Journal

quickly molded to the back of my head. Similarly, another piece was heated and molded to the front of my face. It felt extremely warm, but it did not burn. The back and the front pieces clipped together at two points on each side of my head. Breathing through the mask was not a problem. The final step was to add more cement to attach the prosthesis to the bottom of the face mask. Once this dried, the sides of the mask were unsnapped. The technicians worked quickly and were very reassuring throughout the entire process.

I went for a CAT Scan wearing my newly constructed mask. A box was placed over my entirely masked head that would be marked precisely with sight markings for my tumour. It felt dark and awkward, but the staff worked quickly to slide me and all the apparatus into the CT machine. The task was completed in 20 minutes. The image files were on their way for radiotherapy treatment planning. Later that same day I had another MRI without my mask. I do recommend that one keep eyes closed during an MRI. I've had over 10!



Two weeks later, my LINAC treatments began. I was ushered into the radiation room. Lying on my back, I positioned myself on to the back half of my mask that was cradled between my upright arms. I was then handed the front half to put on by first placing the prosthesis in my mouth. When the buckle points were aligned, the technicians snapped the two halves together. This required super human finger strength due to the snug fit. Next, they put the sight marking box over my head and fastened it to the metal frame holding the mask. The ultraviolet lights were dimmed so that the technicians could see the projected red sight lines lined up accurately to the LINAC.

The box was removed, and the room lights turned up. The machine, the cot and myself were in position for the first beam. Everyone left the room and the heavy door was closed. Outside, the technicians had a control panel and screens to view my image. Beams of radiation were shot. The beam makes a loud, droning noise, each lasting about twelve seconds. I felt nothing as the tumour was being treated. There is a flag available to hold in case of trouble. After five sequences, they returned to unsnap my mask. My bed was lowered, and I abandoned "ship". Set up times varied from fifteen to forty minutes to ensure the accuracy of the beams. I sometimes counted to help me overcome claustrophobia. It was critical to remain still.

I met with my radiation physician once a week at the clinic. At my final visit, he advised that the effects of the radiation would peak over the following two weeks. My impression is that I suffered few side effects from the LINAC treatment.

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The first weekend I recall some nausea but did not warrant medication. I found eating soon after each treatment kept my tummy comfortable. After session #18, patches of hair, the size of a loonie fell out in the shower. However, my hair regrew back within 5 weeks. I began to feel tired by the end of the series of treatments. Early in the sessions, I thought my hearing cleared but the old plugged feeling returned. I continued to feel some dizziness in bed at night. My follow-up audiograms and MRI's continued every six months for two years.

My hearing remained unchanged. The hearing in my left ear was diminished as it was prior to treatment. Also, there was no change in the tumour. However, the next MRI indicated the tumour shrank from 1.7 cm. to 1.5 cm. Shrinkage occurred on all sides. Follow-up appointments changed to yearly. On another positive note, I felt more energetic and my balance problems had lessened. At my annual appointment in 2004, Dr. McKenzie shared positive reports about both hearing assessments and tumour appearance. I had no dizziness, loss of balance or untoward symptoms. My appointments were shifted to two-year intervals.

By 2010, Dr. McKenzie rewarded me with the report "no new growth" and signs of tumor shrinkage. He said he never wanted me to come back.

That, friends, is my story. As I reviewed the data, I was reminded how fortunate I am. How blest to have help along the journey. These tumours take away your hearing, in exchange for tinnitus, imbalance, confusion, fatigue, pain and dizziness. However, as human beings, we can be resilient, we can adapt, we can learn new ways of coping, and we can offer support to each other.

I now volunteer as intervenor with a deaf, blind lady using my ASL. She teaches me hard lessons about patience but gives me so much joy in living. I love my three beautiful daughters and my son who hangs my mask in his Band Room in Victoria. And my nine grand children and two great grand children. Two years ago, I got red hearing aids in both ears. I guess it was time...even though I have no tumor in my right ear!

Addendum

The Vancouver Cancer Clinic LINAC machine was adapted for brain tumors in 1997. The LINAC 2 machine has since been replaced twice as it has a 10-year life span. It is now called the TRUE BEAM S10X. (x-ray)

Joe Navarro, author, speaker, and former FBI agent:

"We are more powerful, more knowledgeable, better prepared than we think we are."

Don't you love hearing this? What a marvelous reminder to turn within for our power, knowledge, and ability to live life on our own terms. Other people may inspire us, but it is each of us as individuals that has the given power to flourish in all aspects of our lives.

Acoustic Neuroma Research Abstracts

PubMed.gov

U.S. National Library of Medicine, National Institutes of Health

Functional Preservation After Planned Partial Resection Followed by Gamma Knife Radiosurgery for Large Vestibular Schwannomas.

Iwai Y¹, Ishibashi K², Watanabe Y², Uemura G³, Yamanaka K⁴.

Objective:

The treatment goal for vestibular schwannomas (VS) has been changed from total removal of the tumor to functional preservation with long-term tumor growth control. The small- to medium-sized VS can be treated by stereotactic radiosurgery, but large VS require surgical decompression for the relief of cerebellar dysfunction and increased intracranial pressure. We have been performing planned partial surgical resections followed by gamma knife radiosurgery (GKS) for large VS. Here, we evaluate a recent series of such cases from the standpoint of functional outcomes.

Methods:

From January 2000 to May 2013, we treated 40 patients with large unilateral VS (maximum tumor diameter at least 25 mm) with planned partial tumor removal followed by GKS for functional preservation. The median maximum diameter of the tumors was 32.5 mm (range 25-52 mm). All patients underwent surgery via the retrosigmoid approach, and tumors situated on the ventral and in the internal auditory canal intentionally were not removed, thus preserving cranial nerve functions. GKS was performed 1-12 months after surgical resection (median interval 3 months). The median tumor volume at GKS was 3.3 cm³ (range 0.4-10.4 cm³) and the median prescribed dose was 12 Gy (range 10-12 Gy). The median follow-up period after GKS was 65 months (18-156 months).

Conclusions:

Planned partial removal of large VS followed by GKS achieved a high rate of facial nerve and hearing preservation. To achieve long-term tumor growth control, the tumor volume at GKS after planned partial surgical resection should be smaller than 6 cm³. Our results revealed that patients with hearing preservation postoperatively have a chance of maintaining hearing function, even though the possibility exists of deterioration by long-term follow-up after surgical intervention and GKS. Furthermore, some patients with severe hearing loss before treatment have the chance of hearing improvement, even those with large VS.

World Neurosurg. 2015 Aug;84(2):292-300. doi: 10.1016/j.wneu.2015.03.012. Epub 2015 Mar 16. Copyright © 2015 Elsevier Inc.

Acoustic Neuroma Research Abstracts

Gamma Knife Surgery for Patients with Facial Nerve Schwannomas: a Multi-Institutional Retrospective Study in Japan.

Hasegawa T¹, Kato T¹, Kida Y², Hayashi M³, Tsugawa T⁴, Iwai Y⁵, Sato M⁶,
Okamoto H⁷, Kano T⁸, Osano S⁹, Nagano O¹⁰, Nakazaki K¹¹.

Objective:

The aim of this study was to explore the efficacy and safety of stereotactic radiosurgery for patients with facial nerve schwannomas (FNSs).

Methods:

This study was a multi-institutional retrospective analysis of 42 patients with FNSs treated with Gamma Knife surgery (GKS) at 1 of 10 medical centers of the Japan Leksell Gamma Knife Society. The median age of the patients was 50 years. Twenty-nine patients underwent GKS as the initial treatment, and 13 patients had previously undergone surgery. At the time of the GKS, 33 (79%) patients had some degree of facial palsy, and 21 (50%) did not retain serviceable hearing. Thirty-five (83%) tumors were solid, and 7 (17%) had cystic components. The median tumor volume was 2.5 cm (3), and the median prescription dose to the tumor margin was 12 Gy.

Results:

The median follow-up period was 48 months. The last follow-up images showed partial remission in 23 patients and stable tumors in 19 patients. Only one patient experienced tumor progression at 60 months, but repeat GKS led to tumor shrinkage. The actuarial 3 and 5-year progression-free survival rates were 100% and 92%, respectively. During the follow-up period, 8 patients presented with newly developed or worsened pre-existing facial palsy. The condition was transient in 3 of these patients. At the last clinical follow-up, facial nerve function improved in 8 (19%) patients, remained stable in 29 (69%), and worsened in 5 (12%; House-Brackmann Grade III in 4 patients). With respect to hearing function, 18 (90%) of 20 evaluated patients with a pure tone average of \leq 50 dB before treatment retained serviceable hearing.

Conclusions:

GKS is a safe and effective treatment option for patients with either primary or residual FNSs. All patients, including one patient who required repeat GKS, achieved good tumor control at the last follow-up. The incidence of newly developed or worsened pre-existing facial palsy was 12% at the last clinical follow-up. In addition, the risk of hearing deterioration as an adverse effect of radiation was low. These results suggest that GKS is a safe alternative to resection.

World Neurosurg. 2015 Aug;84(2):292-300. doi: 10.1016/j.wneu.2015.03.012. Epub 2015 Mar 16.



Upcoming Chapter Meetings Planned

KITCHENER – WATERLOO CHAPTER

Date: Saturday April 21, 2018 – 10am – 12pm followed by a potluck lunch
Location: Home of Tom & Helen Horlings
 #30 – 50 Bryan Court, Kitchener, ON N2A 4N4
Guest Speaker: David Schroevalier a registered massage therapist, Schroevalier Therapeutics. He has experience with the unique issues with acoustic neuroma patients.
For more info: Linda Darkes
 (519) 696-3445 / pdarkesc659@rogers.com
 Helen Horlings
 (519) 954-5581 / healto@rogers.com

BRITISH COLUMBIA: COURTENAY/NANAIMO CHAPTER

Date: Saturday April 14, 2018 – 12 noon – 3pm
Location: Atrium at Crown Isle Resort & Golf Community
 399 Clubhouse Drive, Courtenay, BC
Guest Speaker: Jennifer Frey, MSc, RAud, RHIP of Connect Hearing will address aural rehabilitation including optimizing remaining hearing, tinnitus management and devices.
For more info: Evalyn Hrybko
 (250) 282-3269 / wehrybko@saywardvalley.net

TORONTO CHAPTER

Dates: Tuesday, May 29, 2018
 Tuesday, July 31, 2018
Location: Canadian Hearing Society
 271 Spadina Road, Toronto, ON (Parking in the rear)
For more info: Lynda Nash
 (416) 282-0036 / lynda_lu123@sympatico.ca
 Kathryn Harrod
 (905) 891-1624 / kath.harrod@live.ca

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