The Connection

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## Watch and Wait or Radiate? Some Food for Thought

*By: Luke Hnenny MD, FRCSC, FAANS and Paul Mick MD, FRCSC, MPH; Divisions of Neurosurgery and Otolaryngology, Royal University Hospital, Saskatoon*

Dr. Luke Hnenny

Dr. Paul Mick

In recent decades, access to CT and MR imaging has increased dramatically. This has resulted in earlier diagnosis of vestibular schwannomas. Many tumours are now diagnosed when they are still small or medium in size and have not yet caused severe hearing or balance problems. Significant uncertainty exists as to the best management strategy for these tumours. As for any vestibular schwannoma, management options include both treatment and observation (so-called "watchful waiting"). Treatment involves either stereotactic radiosurgery (SRS) or microsurgical resection. Observation involves MRI surveillance (typically yearly for five years, then less frequently if no growth is observed), along with audiometry for monitoring of hearing.

This article will outline the current evidence and thinking regarding the relative risks and benefits of observation versus SRS for small to medium-sized vestibular schwannomas in people with "serviceable" hearing (i.e., people who have normal hearing, or who have hearing loss that can be treated with hearing aids because the sound they hear is still reasonably clear). Microsurgical resection will be excluded for the purposes of this comparison. Please note, however, that microsurgical resection may still be a good option in carefully selected cases.

When comparing management strategies (observation versus SRS) for small and medium-sized vestibular schwannomas with serviceable hearing, tumour control rates and hearing preservation rates should be examined in detail.

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Facial nerve preservation rates can also be considered, but the rates of facial nerve preservation with both SRS and observation are very high. Finally, there are several other potential adverse effects of observed and/or irradiated vestibular schwannomas that bear mentioning.

With observation, the tumour growth rates in the literature vary quite widely. According to the 2019 European Association of Neuro-Oncology (EANO) guidelines, approximately 50% of newly diagnosed vestibular schwannomas will grow in the first five years following diagnosis, with a mean growth of 3 mm/year. Although numerous studies have attempted to determine what factors may predict growth (for example, tumours confined within the internal auditory canal are thought to grow less frequently than tumours that are growing outside of the canal), there is no reliable way to determine which tumours are more likely to grow and which are more likely to remain stable.

With SRS, tumour control rates have been shown to be very good in the short and medium term. In one large series from the University of Pittsburgh, tumour control was assessed in 871 patients treated with SRS for vestibular schwannomas of all sizes. Tumour control rate, reported as progression-free survival (meaning the tumour didn't grow), was 97% at three years, 95% at five years, and 94% at ten years. Smaller tumours were associated with a longer progression-free survival. As expected, SRS provides a significantly better tumour control rate than observation.

Now what about hearing preservation? With observation, according to the EANO guidelines, approximately 50% of patients with serviceable hearing upon diagnosis of a vestibular schwannoma lose their hearing within 3-4 years. The Congress of Neurological Surgeons (CNS) guidelines suggest that in a patient with normal hearing upon diagnosis, there is a 75-100% probability of maintaining serviceable hearing at two years and a 50-75% chance at five years with observation. It is thought that good speech discrimination function at the time of diagnosis may predict longer-term hearing preservation with observation.

With SRS, hearing loss also occurs. In the same large series from the University of Pittsburgh, 326 of the 871 patients had serviceable hearing on diagnosis. Of these, 90% maintained serviceable hearing at one year after SRS, 77% after three years, 68% after five years, 63% after seven years, and 51% after ten years.

What are the facial nerve preservation rates with each management option? With observation, facial weakness is essentially unheard of, even with very large tumours. With SRS, approximately 1-2% of patients will develop a transient facial weakness after treatment, but this is predominantly in patients with larger tumours.

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Other adverse effects of observed and/or irradiated vestibular schwannomas such hydrocephalus and trigeminal neuropathy (facial pain/numbness) are extremely uncommon in small and medium-sized tumours regardless of management strategy. Malignant transformation of a vestibular schwannoma either spontaneously or as a result of SRS is also exceedingly rare, although this risk is higher in patients with Neurofibromatosis Type 2.

What are we to make of this information? Is it better to observe small-medium vestibular schwannomas in patients with serviceable hearing, or to treat them straight off with SRS? Both strategies eventually result in hearing loss, but SRS provides significantly better tumour control. However, a certain percentage of these schwannomas may not grow for an extended period of time, and perhaps hearing can be preserved longer by simply observing them. The ideal management strategy would result in excellent tumour control, while maximizing the duration of serviceable hearing.

There is some more recent literature that suggests early SRS may result in prolonged serviceable hearing when compared with observation. A February 2021 paper from the Pittsburgh group looks at patients who underwent SRS with Gardner-Robertson (GR) I (normal) hearing and compared them to patients who were initially GR I but worsened to GR II (impaired but serviceable) while waiting for SRS. The patients having SRS with GR I hearing had hearing preservation rates after SRS of 80% at three years, 63% at five years, and 51% at ten years. Patients whose hearing deteriorated to GR II while waiting for SRS had hearing preservation rates after SRS of 40% at three years, 33% at five years, and 20% at ten years. They recommend early SRS, before loss of hearing occurs, to optimize duration of hearing preservation. Another paper from a French group in 2010 comes to a similar conclusion with regard to small intracanalicular tumours.

For now, the EANO continues to recommend in its guidelines, observation for incidental, asymptomatic vestibular schwannomas. Given some of the newer evidence regarding hearing preservation with early SRS, specifically the Pittsburgh paper from this year, our group is proposing SRS as a reasonable option for these patients as well. A randomized, observer-blinded controlled trial is set to attempt to answer this question more definitively. Piloted by a Norwegian group, the Vestibular Schwannoma: Radiosurgery or Expectation (V-REX) study will compare observation with SRS over a four-year period. Hopefully this study will provide some more definitive direction for patients and surgeons grappling with this decision.

Despite the voluminous data available to patients and physicians deciding how to manage small-medium vestibular schwannomas among patients with serviceable hearing, it remains a very personal decision for each patient. Each patient is unique, not only with regard to his/her tumour,

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but with regard to his/her life situation, risk tolerance, psychology, and feelings about his/her condition. The job of the physician is to help guide patients to make the decision that is right for them, taking all these factors into account.

***The Saskatchewan Skull Base Program was initiated in 2018. Up to that point, skull base surgery patients in Saskatchewan were cared for by any one of the many neurosurgeons along with their otolaryngology colleagues in Saskatoon and Regina, or travelled out of province for treatment. The advent of the program has concentrated skull base surgery into the hands of primarily subspecialty fellowship-trained neurosurgeons and otolaryngologists at the University of Saskatchewan, in Saskatoon. Comprehensive care is available for the breadth of skull base pathology, including tumours (vestibular and other cranial nerve schwannomas, pituitary adenomas, craniopharyngiomas, skull base meningiomas, chordomas), as well as non-tumour conditions such as cerebrospinal fluid leak, encephalocele, and superior semicircular canal dehiscence. A multidisciplinary approach is emphasized, and the program includes not only surgeons, but also audiologists, intra-operative electrophysiologists, endocrinologists, neuropathologists, neuroradiologists, endovascular neurosurgeons, and neuropathologists.***

***The multidisciplinary vestibular schwannoma clinic is conducted monthly by both Drs. Luke Hnenny (neurosurgery) and Paul Mick (neuro-otology/skull base surgery), where patients with newly-diagnosed vestibular schwannomas are assessed, and post-treatment patients are followed. Although stereotactic radiosurgery (SRS) is not currently available for patients with vestibular schwannomas in Saskatchewan, the Saskatchewan Skull Base Surgery Program has excellent working relationships with SRS programs in both Manitoba and Alberta.***

***In addition to ongoing growth and sophistication in the clinical program, clinical research is ongoing. The program is also involved in the training of medical students and residents at the University of Saskatchewan.***

***Any questions about the program can be directed to Dr. Luke Hnenny (luke.hnenny@saskhealthauthority.ca) or Dr. Paul Mick (paul.mick@saskhealthauthority.ca).***

**Albert Einstein was obsessed with science. He didn't only develop the theory of relativity and other theories that changed the way we see and experience the world, but he also left us with wisdom on how to live better lives.**

**"It is not that I'm so smart. But I stay with the questions much longer."**

**There are many paths to success, but one of the few similarities of successful people is *persistence*.**

# Member of the AN Quarter Century Club

*By: Dr. Neil Davis, MD, Montreal, Quebec*

May 8th, 2021 will mark 25 years since the surgery that saved my life.

At the time, I was a 21-year-old university student pursuing a Bachelor's degree in psychology at McGill. I wasn't yet sure what I wanted to do with my life. I had considered medicine, but in the months leading up to my diagnosis, had begun to question that path. I was considering dentistry, optometry, law, and even becoming a rabbi. I had broken up amicably with a long-term girlfriend and had set my interest on another young lady who sat next to me in one of my classes. Things were good. Aside from the fact that for some reason I couldn't hear as well in my left ear as I could in my right – a situation that was becoming more pronounced over time – all was well with my world.

Then one morning in mid-March I was sitting in organic chemistry class when my professor's voice became suddenly quiet and was replaced by an overpowering ringing in my left ear. I had experienced tinnitus before but had never heard it this loudly. As the day progressed, the tinnitus quieted but the hearing in that ear never quite returned to baseline. That night I reported the problem to my father, a medical doctor, who asked one of his ENT colleagues if he'd mind seeing me right away.

I had seen my GP about my hearing loss once before but he had not been alarmed. In contrast, the ENT surgeon in whose office I found myself the following morning was visibly shaken by my story of years of progressive, one-sided hearing loss. He referred me immediately for an audiological assessment, the result of which prompted him to order an urgent CT scan of my head.

With that result – a 2.8 cm acoustic neuroma - everything changed. I was thrown into a whirlwind that need not be described in detail, as most readers of this piece will have experienced their own. The next seven weeks consisted of MRIs, appointments with ENT and neurosurgeons, a trip to Providence, Rhode Island, to meet with Dr. Georg Noren, a pioneer of the then brand-new Gamma Knife (not yet available in Canada) and, of course, studying for my final exams. In retrospect, I don't know how I managed to focus on preparing for the exams with so much else going on, and can only surmise that my determination not to lose any academic time powered me through.

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I passed all my exams, the last of which was on Monday, May 6th. The following morning, I presented myself to the Jewish General Hospital in Montreal to "check in" for my surgery and was assigned a roommate – a gentleman in his 80s who was recovering from open heart surgery. He and I spent much of that afternoon talking and to this day, I'll never forget something he said: "For me, this heart surgery bought me a bit of bonus time, but that's about it; for you, though, the operation that you're having tomorrow will buy you an entire future which will be yours to enjoy as you please. Remember that as you go in." Indeed, Sydney passed away only seven months later, in January of 1997, but I maintained a friendship with his partner Sonia (who we discovered later was a distant cousin of mine!) until her death last year from COVID-19.

With thanks to G-d, a pair of brilliant surgeons, a wonderful anesthesiologist and a talented operating room team, I can report that my translabyrinthine surgery was extremely successful. My first post-op memory is from about 3 A.M – roughly 19 hours after having been put to sleep – and is of my father standing over me saying "complete success" and asking for a confirmatory symmetrical smile. I regained my ability to keep my balance enough to walk over the next five days in hospital, although in truth, my balance remains suboptimal to this day. I can cycle and ski, but walking in the dark is still not a wise idea. Of course, I was also getting used to being completely deaf in my left ear and the host of issues that presents (strategic placement among guests at dinner tables, trying to figure out which elevator dinged, etc.). By the end of May, I was feeling well enough to sign up for a summer class at McGill in order to lighten my academic load for the fall semester.

Although I couldn't possibly name them all, this is a perfect time to thank a few of the innumerable people who have helped me with all of this. My parents, Elaine & Eric Davis and sister Cindy Davis Abramovitch were an amazing support system right from the get-go; Drs. Gerard Mohr (neurosurgeon) and Jean-Jacques Dufour (ENT surgeon), who are about as close to heavenly beings as can possibly exist in my opinion; Dr. Bekhor, anesthesiologist extraordinaire; Shirley Entis, a nurse and then-President of ANAC, Drs. Jamie Rappaport, Shelly Browning and James MacDougall, ENT surgeons and a psychologist respectively, all of whom I did ANAC/ hearing loss-related research with which was published (and which, in retrospect, was a great help in subconsciously processing what I had been through). The list goes on.

The Acoustic Neuroma Association of Canada (ANAC) was a critical resource after my diagnosis and throughout my recovery, and I tried to pay it forward by joining ANAC's Board of Directors for two years until I began medical school in 1999. I also spent a year doing ANAC-related research at McGill while applying to study medicine. Since then, I've more or less returned to a

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"normal" life – an MD, living in New York and Israel before finally returning to Montreal in 2009 with my American wife Lainie (who has accepted and loved me for who I am, brain surgery "baggage" included), two kids (Zoe and Russell, ages 9 and 7 respectively), a dog named Stanley, a comfortable home, and a wonderful circle of family and friends. But not a day goes by that I don't recall the events of 1996 and think of how lucky I was to be born into an era of modern medicine in the First World. In any other time or place, I would not be writing this today.

I recognize that, at the age of 21, I was exceptionally young to develop a non-NF2 acoustic neuroma and am more than happy to connect with any patient, especially ones who are dealing with it so early in life.

Please feel free to contact me. Neil Davis, Montreal (neildavismd@hotmail.com)

***This story is sponsored by Dr. Neil & Lainie Davis in celebration of the 25th anniversary of his acoustic neuroma surgery - May 8, 1996".***

## What is Tinnitus and How is it Treated?

***By: Rex Banks, Au.D., Reg. CASLPO***
***Doctor of Audiology, Director of Hearing Healthcare, Quality and Knowledge Enterprise, Canadian Hearing Services***

Tinnitus is the perception of sound that has no external source and can generally only be heard by the person experiencing it. But how do we hear a sound that isn't really there? The answer is found in our central nervous system.

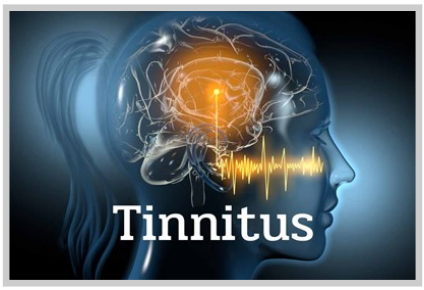
Our central nervous system is in a constant idle state, ready to respond to any possible encounters. This idling causes background "brain noise". Most of us are unaware of this noise until something triggers it and causes it to become audible.

Your ears are always working but they relax when they find a soothing sound to listen to. They are geared to naturally want to listen to sound and are always scanning the environment for it.

For people with hearing loss, the amount of sound they are exposed to is reduced. This causes them to strain to hear the sounds around them. All of this straining increases their sensitivity to brain noise, which manifests as tinnitus.

# What is Tinnitus and How is it Treated?

It is important to understand that tinnitus is not a disease, but rather a symptom. Some of the leading causes are hearing loss, exposure to loud noises, ear trauma, stress and certain medications. And yes – an acoustic neuroma can also cause tinnitus!




An estimated 37% of adult Canadians experience tinnitus each year. But the experience is unique in everyone. Noises like ringing, humming, buzzing or even cricket like chirping are all referred to as tinnitus. For 7% of people who experience tinnitus, it is bothersome, meaning it affects their sleep, concentration, or mood.

The severity and persistence of tinnitus can range from a short-term occurrence of no consequence to a chronic and life-interfering condition. Tinnitus has been associated with anxiety and depression, insomnia, irritation, stress, and even suicide, although the latter may be a reflection of comorbid mental health problems.

There is no cure for tinnitus; management focuses on quality of life and varies depending on factors such as severity, impact, comorbid hearing loss and individual needs. A personalized approach to treatment is recommended. If you have tinnitus, you should avoid silence as it only intensifies your sensitivity to tinnitus. For this reason, hearing aids are often recommended as a frontline defense against tinnitus since hearing aids expose people with hearing loss to sound. For those who experience tinnitus but do not have hearing loss, custom ear sound generators may be recommended. Another option is tinnitus retraining therapy (TRT), which retrains the subconscious part of the brain to ignore or habituate to tinnitus. This involves the use of sound therapy, along with education and counseling, which helps reduce stress and anxiety about tinnitus. Medications may be prescribed for tinnitus, particularly when comorbid conditions such as depression or insomnia are present. Cognitive Behavioral Therapy (CBT) may also be recommended. CBT does not aim to eliminate tinnitus, but to reduce one's negative response to it. Alternative medicine, such as acupuncture, ginkgo biloba, zinc supplements and so forth, have not been well-studied and their efficacy is questionable.

If you think you are experiencing tinnitus, contact an audiologist or your ENT physician as a starting point. Some of the most helpful things you can do is to get information, not dwell on your tinnitus or catastrophize the situation. The reality is there are no guarantees or quick fixes for tinnitus and in my experience, bouncing from treatment to treatment rarely produces a positive outcome. Find someone you trust who is empathetic, knowledgeable and offers an evidence-based approach to treating tinnitus. Finally, stay positive. If tinnitus can happen, it can unhappen.

# What is Tinnitus and How is it Treated?

***Rex Banks has been an audiologist for more than 30 years and has worked at Canadian Hearing Services since 2001 where he is the Director of Hearing Healthcare, Quality and Knowledge Enterprise. He oversees CHS' Audiology and Speech-Language Pathology programs, quality and accreditation initiatives, and develops knowledge-based products and infection control protocols.***

***Rex completed his Au.D. (Doctor of Audiology) degree from A.T. Still University of Health Sciences where he was the recipient of the Professional Leadership Award in Audiology and is now an Adjunct Assistant Professor in the Post-Professional Doctor of Audiology Program. He received his M.A. in Audiology from the University of Tennessee and B.A. in Communication Disorders from the University of Mississippi.***

***Rex has held multiple professional and advocacy roles including being a former President of the Canadian Academy of Audiology (CAA), the Ontario Association of Speech Language Pathologists and Audiologists (OSLA) and the Acoustic Neuroma Association of Canada (ANAC). He was the inaugural recipient of OSLA's Audiologist of the Year award. Additionally, he is a certified Teacher of English as a Foreign Language (TEFL) and volunteers his time to help internationally trained audiologists pass English language proficiency exams to work in Canada. Rex's audiology experience spans private practice, ENT physician offices, hospitals, universities, and the non-profit sector. As well, he is trained in Tinnitus Retraining Therapy (TRT).***

# Docs Team Up for a Kid: Rare Cases Call for Rare Measures

## *By: Ben Espey, Toronto*

Ben and Beloved Tessa

It all started in my Grade 9 homeroom classroom. The teacher didn't mind if we listened to music so I had both my headphones in but realized that I couldn't hear much of anything in my right ear. I assumed that my right headphone must be broken. For the next few months, I only ever used my left headphone. I finally realized that it wasn't a problem with the headphone at all, but with my actual ear. I didn't tell my parents right away because I didn't think it was a big deal; I thought that my ear might just be plugged because of a cold or allergies. Boy was I wrong!

After a few weeks I finally told my parents about my hearing issues. We went to my family doctor to see what was the problem, thinking it would just be a wax build up. The doctor looked in my ear but couldn't see any visible problems. He suggested that I go for a hearing test and also referred me to an ENT specialist. The hearing test didn't go too well and the ENT ended up sending me for an MRI. The results revealed the problem: a 2.5 cm mass on my acoustic nerve. An acoustic neuroma was a term I'd never heard before but one I would become far too familiar with. I just kept thinking, "How can this be possible? I'm a kid!" My parents and I did a lot of research about my condition and found ANAC, which turned out to be a huge support.

# Docs Team Up for a Kid: Rare Cases Call for Rare Measures

Since I was still a minor, I was sent to the Hospital for Sick Children in Toronto (SickKids), where I stayed for a few nights. During my stay at SickKids, they ran different tests and monitored me to confirm the diagnosis. This was very weird for me as I felt completely normal and like myself. The doctors explained that although the tumour was benign, it was extremely rare in children and could be very serious. After a lengthy discussion with the physicians, myself and my family, my doctors recommended waiting and monitoring what happens, as this type of tumour is slow growing. Every three months, I would go to SickKids for a series of tests, which included an MRI and a hearing test.

After my mom reached out to ANAC, its executive director Carole Humphries suggested she attend the World of a Vestibular Schwannoma Symposium in 2018, where she would have an opportunity to approach Toronto Western Hospital's Dr. Gelareh Zadeh in person, one mother to another. The first request had been turned down based on the policy regarding care for children.

As a result, Dr. Zadeh, called by some a rock star in neurosurgery now head of neurosurgery at the University Health Network and Director of Krembil Brain Institute, was brought on to work with a team of doctors at SickKids. I felt very lucky to have so many experts taking care of me. The tumour continued to grow but I was having no symptoms other than hearing loss. Being an active 15-year-old kid, I went on with my life: going to school, playing hockey and hanging out with friends. Over the years, I never felt like this tumour was holding me back from doing anything; it was just something that I lived with. My hearing never got much worse and I just learned to deal with it. The scary part was that I knew at some point I would need to get surgery to remove this tumour but I didn't know exactly when.

It wasn't until I was seventeen that the doctors at SickKids Hospital and Toronto Western Hospital agreed that we should go ahead with surgery. I was very nervous in the weeks leading up to my surgery but the doctors and my family were very reassuring. The uncertainty of what would happen post operatively – was what scared me the most. I had come to terms with the fact that I would most likely lose some if not all of my hearing in my right ear but there were many other complications that could occur.

On the day of the surgery, I tried to stay as calm and level-headed as possible. I walked in through the hospital doors with my head held high, ready for anything. On the inside I was freaking out. Once I was in the operating room, the surgeons and nurses were very friendly and kind. I remember them asking me what I would be doing at that moment if I wasn't at the

# Docs Team Up for a Kid: Rare Cases Call for Rare Measures

hospital. I said I would probably be out golfing with friends. The conversations that I had with the nurses in the minutes leading up to my surgery comforted me and reassured me that I was in the right place to get this surgery done. Within ten minutes, I was asleep.

For me it was a very quick procedure; I went to sleep, then woke up. ln reality, it took close to ten hours. I woke up in the ICU and was asked to perform different exercises with my face to see if I had lost any facial function. Luckily, I had not. At this point I could barely keep my eyes open; I was so tired. I was taken to the recovery room, where my mom was waiting for me. Since my surgery was done during the Covid-19 pandemic, I was allowed only one visitor at a time. Because we live in Uxbridge, my parents took time off work and booked a hotel close to the hospital so they could be there at this very important time in my life. This meant that my mom and dad were able to take shifts to be with me. They would each spend 24 hours with me and then switch over.

After a day in the recovery room, I was up and walking, I didn't have much energy at that point and could only stay awake for a few hours at a time. I was discharged from the hospital after only three days and went back to my home. I wasn't able to do much physically for about a month. But now almost three months since my surgery, I'm feeling almost 100 percent except for my loss of hearing. I'm "learning to live with it."

I am going to school, working and going to be able to get back on the ice to play hockey in 2021. I am getting ready to go to university this coming year and hope to attain a business degree. I just had another MRI done at Markham Stouffville Hospital and had a consultation with Dr. Zadeh over the phone. She said that it is looking very good and healing properly. From now on, I will only need to get MRIs done every six months to a year for the time being.

I am just very thankful for all the doctors and nurses that helped make this process as good as it could be, and, of course, to my parents for going the extra mile to support me. I was very lucky and blessed to come out of this surgery with very few issues. What I have learned through this process is that by staying positive and surrounding yourself with positive people, you can get through anything.

**Earl Nightingale, author and motivational speaker reminds us to:**

**"Never give up on a dream just because of the time it will take to accomplish it; the time will pass anyway."**

**What a powerful piece of encouragement. Time will pass no matter what. So, you might as well focus on your dream. To do otherwise is to abandon the very thing you most want to achieve and then the time will be gone anyway.**

# The Journey Toward My Acoustic Neuroma Treatment Plan

***By: Shelley Lacroix, Ottawa***

My story began with a simple ear ache that would not go away. After trying an off-the-shelf antibiotic and, subsequently, a cortisone prescription to no success, I was referred to the ENT clinic at the hospital.

The doctor at the clinic told me that I had age-related hearing loss. I had a hard time accepting this. My hearing up to that point had not been an issue. My tests showed 60% hearing in one ear and 80% in the other with 100% speech recognition. On the off-chance that my condition was attributable to sudden hearing loss, my doctor treated me with four intratympanic dexamethasone injections in my middle ear. I assure you that was not a pleasant experience! I continued to experience pressure and aural fullness in my ear. At times, it felt like something was pushing against my tympanic membrane. I was then prescribed a course of Prednisone which led to no change in my condition. At this point, another doctor in the clinic referred me for a contrast MRI. In spite of the doctor's request, the technician refused to give me contrast. As a result, I had to return for a second MRI after the first one revealed there was indeed a problem!

My contrast MRI report indicated that I had an acoustic neuroma (AN) measuring approximately 2 x 1.8 x 1.4 cm, approximately the size of a pecan half. I was relieved to learn that it was benign. During a video-conference with an ENT surgeon and neurosurgeon, the ENT surgeon informed me that I was not a suitable candidate for middle fossa surgery because my acoustic neuroma was too big. Alternatively, the neurosurgeon proposed translabyrinthine surgery which would result in complete hearing loss, a severed vestibular nerve and could lead to partial facial paralysis or numbness and the possibility of a permanent or temporary palsy (droopy eye and droopy lip). Who wants to gamble with that I thought?

I bought myself time by agreeing to accept a "wait and see" approach in monitoring the growth of my AN. I made it my personal goal to learn as much as I could on the topic of ANs and treatments available in Europe, Canada and the USA. I am glad that I did this as soon as possible as I discovered that my treatment options would become limited if I waited too long to address my condition. I read journal articles from the Journal of Ontology and Neurotology including a study about Aspirin halting the growth of sporadic vestibular schwannomas. I came across a study from Harvard where stem cells had been injected in the cochlea of mice to restore cilia and hearing. Unfortunately, no human trials have been undertaken.

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I also explored whether the palsy could be surgically treated and consulted two independent doctors. The otolaryngologist, specialist in head and neck surgery, told me about the problems related to droopy mouth surgery and facial paralysis, and recommended the CyberKnife as the best course of treatment. I also consulted an ophthalmologist who said it was impossible to correct a drooping eye and achieve a natural look.

After receiving this information, I proceeded to conduct extensive research to explore alternative treatments. Through my research, I found out that Munich, Germany, has the most current CyberKnife S7. According to Medical Device News Magazine, the S7 offers "advanced precision, real time artificial intelligence, motion tracking and delivers radiation treatment in as little as 15 minutes". I contemplated flying to Munich for treatment but then…COVID made things very complicated to do that safely. Along the way, I learned that Canada doesn't have a CyberKnife S7 (2020 generation) and my city has the CyberKnife VSI (2009 generation). Also, I discovered that Hamilton and Montreal have CyberKnife M6 (2012).

Determined to find a better solution, I explored various US options in California, Colorado, Florida, Connecticut, and Pennsylvania, among others. During this research, I discovered a link to the American Acoustic Neuroma Association (ANA) and read the information provided by this group. By this time, my husband engaged in my research and stumbled upon the Acoustic Neuroma Association of Canada (ANAC). What a revelation! I became a member and immediately received a phone call from Carole Humphries, Executive Director, who offered both research and evidence-based data. The publications answered most of my questions, but not all. Within 24 hours, Carole connected me with dozens of people across Canada who shared their experiences. This made me realize I was not the only one facing this rare tumour.

It was through ANAC that I learned about Gamma Knife. Carole indicated that Gamma Knife was an alternative to CyberKnife. It was then that I realized that I had been far too focused on CyberKnife.

From that point on, I channelled my energy into exploring the pros and cons of both CyberKnife and Gamma Knife. From the University of Virginia Medical School website, I learned that Gamma Knife is far less invasive than surgery, uses 100X less radiation than CyberKnife and has a radiologic accuracy better than 0.3 mm. The Rocky Mountain Gamma Knife Centre website in Colorado indicated that Gamma Knife has a radiological accuracy down to 0.15 and that Gamma Knife Perfexion is safer because of its tissue-sparing characteristics, and its headframe prevents patient movement during treatment. According to the Mayo Clinic website, Gamma Knife is 95-97% effective and requires only one session to treat an acoustic neuroma. I gained insights

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from the Journal of Neurosurgery about long-term outcomes following Gamma Knife radiosurgery (GKRS). The low incidence of developing hydrocephalus after GKRS and the preservation of hearing 15 years post Gamma Knife radiosurgery confirmed that Gamma Knife was the right option for me.

According to the Orange County CyberKnife and Radiation Oncology Centre website in California, the CyberKnife requires multiple treatments, is 90% effective, and could damage the outer targeted area. The odds associated with Gamma Knife were in my favour.

After completing the bulk of my research, I requested that my family doctor make a referral to Toronto Western Hospital. I compiled all of the paperwork that she required for the referral (i.e., audiology testing, MRI reports, MRI CD, medical history) to facilitate my Dr.'s task and expedite the referral process to Dr. Zadeh, head of neurosurgery of the University Health Network.

Dr Zadeh offered me two treatment options during a telephone meeting: 1) Rectosigmoid surgery which would preserve my existing hearing in combination with Gamma Knife six months post surgery to treat the remaining tumour; or, 2) Gamma Knife. I opted for the least invasive surgery, and I am currently awaiting word from the Gamma Knife Clinic for the date of my treatment.

During my discussion with Dr Zadeh at Toronto Western Hospital, I was comforted to know that the hospital staff focuses on the quality of life of the patient and that their goals are congruent with those of the patient. I knew my goals and shared them with the surgeon in order to ensure quality of life. My goals were simple: preserve my hearing, preserve my facial nerves, and preserve my vestibular nerve. From my standpoint, any treatment satisfying these goals would allow me to live my life to the fullest.

My journey made me wonder how many people out there would have relied on one opinion and had the translabyrinthine surgery with its inherent risks, as proposed by the first surgeon. I was thankful that I connected with ANAC and was able to be guided in the right direction to a team of leading neurosurgeons and researchers in the area of acoustic neuromas and brain surgery. It is important for us to realize that perhaps surgeons recommend surgery because that is their specialty. I was so pleased to learn that Dr. Zadeh and her team do both microsurgery, and stereotactic radiation surgery based on the individual needs of the patient and the size of the neuroma. I was happy that I was given alternatives to my treatment plan.

To close off, I would like to leave you with this final thought. It is important to make an informed decision about any recommended medical treatment plan.

# The Journey Toward My Acoustic Neuroma Treatment Plan

You, alone, control the journey and must research your condition and critically examine all the options available. It is critical to formulate precise questions so that the experts can fill in your knowledge gaps. Once you are confident with your understanding of your condition and possible treatments and their associated risks, you can then, if given a choice, select a treatment plan that satisfies your goals.

## Research Abstract

**PubMed.gov**

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

**Rehabilitation of Facial Palsy and Vertigo in Patients with Vestibular Schwannoma**

Müller B, et al. HNO. 2017.

**Background**: Facial palsy and vertigo, as symptoms of vestibular schwannoma (VS) or consequences of its therapy, have a significant impact on patients' quality of life.

**Objective**: This review analyzed current literature on the topic and deduced recommendations for rehabilitation of facial palsy and vertigo.

**Method**: The present review describes a PubMed-based search of the literature of the past 10 years.

**Results**: There is no evidence-based drug therapy for the treatment of acute facial palsy after VS surgery. Several surgical procedures for facial nerve reconstruction, muscle transfer, and static techniques have been established. Physiotherapeutic movement therapy, optimally with biofeedback, seems to improve facial function in patients with post-paralytic syndrome.

Botulinum toxin injections are the method of choice for synkinesis treatment. For treatment of acute and chronic vertigo in patients with VS, the same antivertiginous drugs as for other vertigo patients are used. If the patient shows retained vestibular stimulation function, preoperative intratympanic gentamycin therapy followed by compensation training is a promising approach to decreasing postoperative vertigo. Good vestibular rehabilitation comprises intensive and regular movement training, preferably with real-time feedback and therapy control.

**Conclusion:** There are several conservative, surgical, or combined conservative-surgical treatment options for individualized facial nerve rehabilitation of VS patients, as confirmed by clinical studies. In cases of acute vertigo, standard antivertiginous pharmacotherapy is indicated. In cases of acute and also of chronic vertigo, intensive balance and movement training provides relief.

# Upcoming Chapter Meetings Planned

### KITCHENER—WATERLOO CHAPTER

**Date:** **Wednesday, June TBD, 2021**—7pm—9pm
**Location:** Virtual Meeting—Details to follow.
**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 May 2021 TBD**—10am—12noon
**Location:** Virtual TBD—White Spot, 2299 Cliffe Ave., Courtenay, BC
**For more info:** Evalyn Hrybko
(250) 282-3269 / wehrybko@saywardvalley.net
Caroline Bradfield
(250) 897-3553 / digitalgal@shaw.ca

### TORONTO CHAPTER

**Date:** **Tuesday May 25, 2021**—6:30pm—8:30pm
**Location:** Virtual Meeting TBD—Details to follow.
**For more info:** Kathryn Harrod
(905) 891-1624 / kath.harrod@live.ca
Linda Steele
(416) 993-0065 / lindasteele2@gmail.com

**ANAC**
P.O. Box 1005
7 B Pleasant Blvd.
Toronto, ON M4T 1K2

T: 1-800-561-2622
T: 1-416-546-6426
E: director@anac.ca

Website: www.anac.ca
Facebook: Acoustic Neuroma Association of Canada–ANAC
Twitter: @CanadaAN