

The

Connection



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Summer Edition 2017

The Maritime Lateral Skull Base Clinic: Multidisciplinary Collaboration, Peer Mentoring and Innovation in Patient Care

By: Andrea Hebb, PhD. RN, Dr. Liam Mulroy, Dr. Simon Walling, Dr. David P. Morris



The Maritime Lateral Skull Base Clinic (MLSBC) located in Halifax, Nova Scotia provides coordinated care through Neurotology (Division of Otolaryngology), Neurosurgery and the Atlantic Stereotactic Radiation Program serving a population of more than 2 million people in a catchment area that includes Newfoundland and Labrador, Prince Edward Island, New Brunswick and Nova Scotia. The MLSBC follows over 800 patients with tumours of the cerebellopontine angle (CPA) including acoustic neuromas (AN) or vestibular schwannomas (VS), meningiomas, epidermoid cysts, hemangiomas and glomus jugulare tumours (GJT), among others. The MLSBS receives referrals from patients across Canada with the majority of patients residing in the Maritime Provinces.

of New Diagnoses by Year and Province in Maritime Lateral Skullbase Clinic

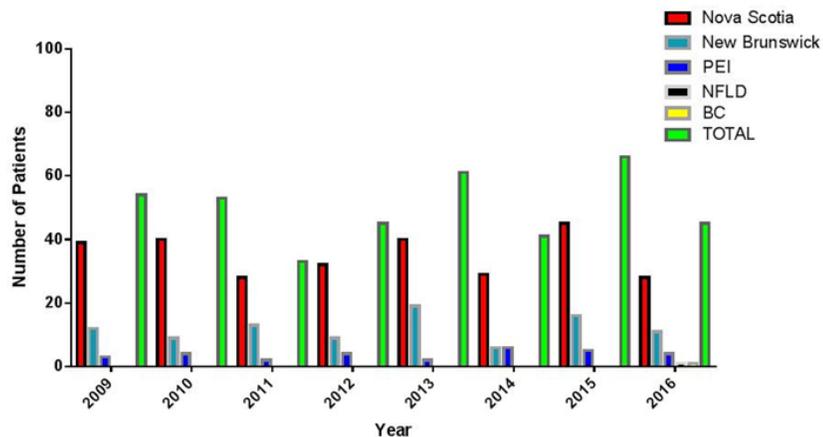


Figure 1: Referrals are received across Canada with the majority from the Maritime Provinces. The number of new patients seen by year per province is outlined.

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Patients are seen in clinic for initial consultation. Patients with relatively small tumours may be given the option for a 'chart check' based on objective criteria, including the general health and mobility of the patient, distance from home to clinic and tumour size. On average, these telephone visits comprise about one third of patient visits.

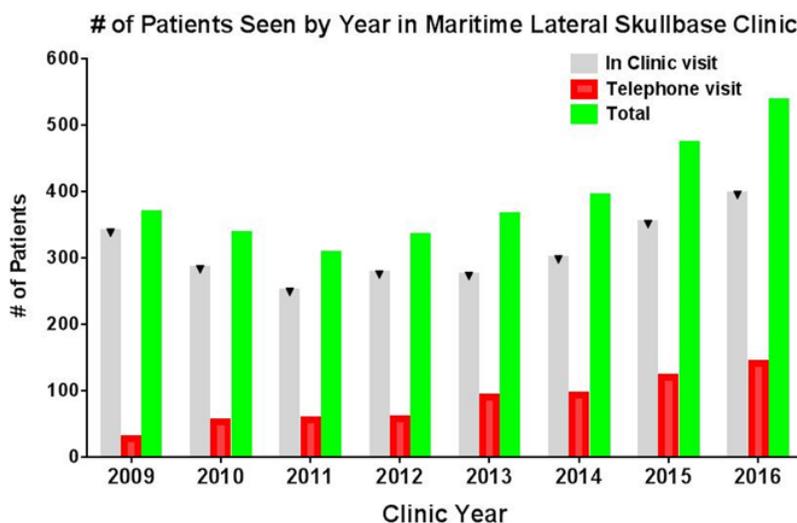


Figure 2: Patients are initially seen in clinic and depending on the stability of their tumor and symptoms patients may be followed periodically by telephone visits or chart checks. Patients are registered in the hospital system, MRI scans are reviewed by the team, the patient is called and a letter dictated to the family doctor. The number of in clinic and telephone visits by year is outlined in the graph. Over 500 patients were reviewed in 2016 and in clinic and telephone visits have been steadily increasing since 2012.

The cohort followed in this clinic also includes patients with genetic conditions such as Neurofibromatosis Type 2 (NF-2), a complex autosomal dominant genetic disorder, in which vestibular schwannoma (VS) otherwise known as acoustic neuromas (AN) occur bilaterally, in addition to multiple other CNS tumours. Nova Scotia is home to several families with NF-2 which each have several affected members. Twenty-eight patients (21 families) with NF2 are followed in this clinic. Management of these families occurs at specialty clinics with increased appointment times allotted in accordance to the complexity of issues these families face.

Our program is unique in Canada in allowing members from all disciplines to formulate management decisions for patients with unilateral or bilateral VS and a range of other lateral skull base tumours in the same clinic. Management strategies include preservation of hearing, balance and coping strategies for tinnitus and vertigo. A recent approach is that of watchful waiting, the "wait and scan" policy. Our group is one of the world leaders in this area. Of utmost importance is that decisions are made with the quality of life of each individual in mind as the cornerstone of

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care: knowing when to and when not to intervene. Currently we are following close to 200 patients with a wait and scan policy. The majority of telephone visit patients would be in this group.

For large or growing tumours the primary treatment options include surgery and/or focused stereotactic radiosurgery. Surgical approaches include translabyrinthine, retrosigmoid, and middle cranial fossa. The surgical options include several approaches designed to save hearing, and some that deliberately sacrifice hearing but more often preserve other vital structures. Stereotactic radiosurgery (SRS) and radiotherapy (SRT) are available locally in Halifax, and we work closely with the stereotactic radiosurgery group. Recently, in addition to Halifax, SRS and SRT are now available treatments in Saint John, New Brunswick. The Stereotactic Radiotherapy Program at Dalhousie University is the referral centre for Atlantic Canadian patients requiring such treatment; irrespective of treating province. Primary indications for stereotactic radiation include documented growth of the tumour and treatment of residual tumour after planned surgical debulking. Generally, tumours up to 2.5 cm in diameter are treated with a dose of 2,500 cGy in 5 fractions whereas larger tumours or those of borderline size with significant brainstem contact are treated with a dose of 5,000 cGy in 25 fractions.

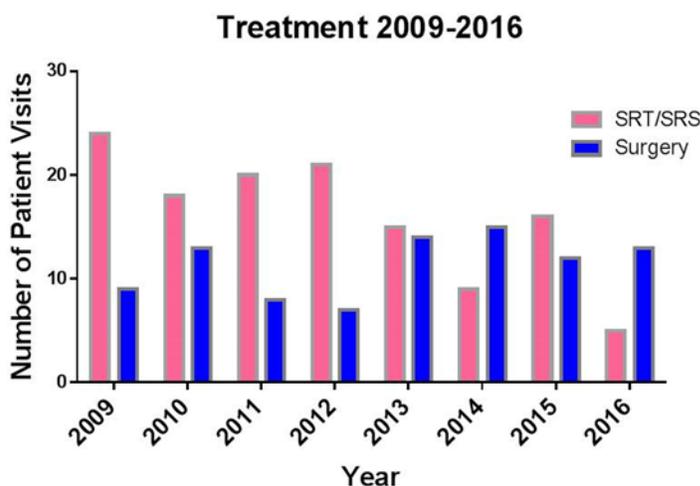


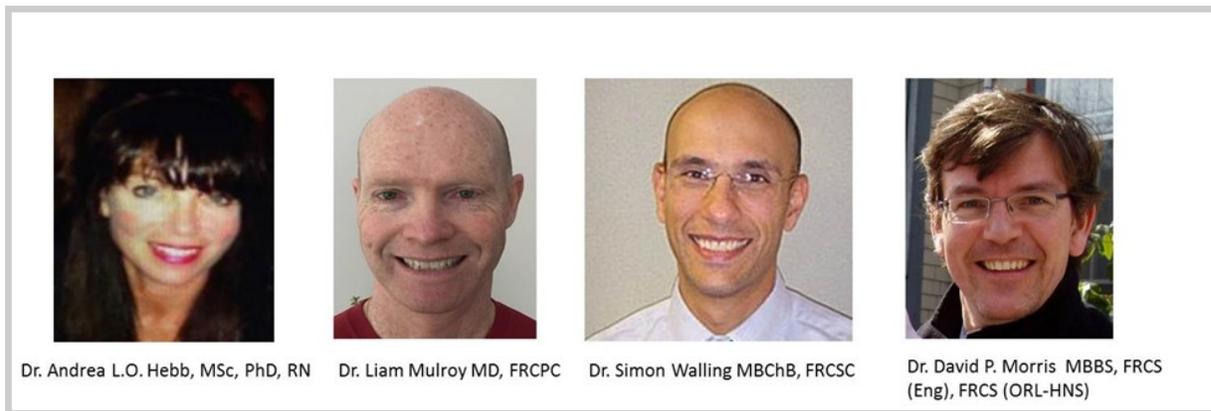
Figure 3: The number of patients treated with SRT/SRS or surgery is outlined per year since 2009.

Following treatment patients are monitored in a multidisciplinary clinic with audiograms and MRI scans every 6 months for 2 years, annually until year 5 and then every second year thereafter. The MLSBC provides an ideal environment in which to identify and intervene in the treatment

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and management of treatment-related side effects. We collect firsthand evidence of the effects of conservative treatment, surgery and radiation treatment in our patients. At each visit, patient's complete quality of life inventories which provide valuable information and target a client centered approach with important implications for treatment decision making.

The goal of our center, through an innovative approach to multidisciplinary care, is to improve clinical management of patients with unilateral or bilateral CPA tumours and a range of other lateral skull base tumours ultimately impacting clinical practice in Nova Scotia and throughout Canada.



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Dr. John F. Demartini, best selling author in human behavior

"Whatever we think about and thank about we bring about."

What we consistently THINK about we bring about. Look at your friends and family members, yourself and your life. What are your predominate thoughts day to day and how do they relate to your life and experiences? As he says: "We can all start to change what we think about when we give THANKS to all that we have. When we feel thankful in our hearts our thoughts become lighter and happier and our lives more fulfilling."

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 under serviced area, please contact Carole Humphries at the National Office for an information package and support.

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Managing Tinnitus: Tips and Tricks



By: Nerissa Davies, MSc, RAUD, RHIP

People with acoustic neuromas may experience tinnitus, or the sensation of sound where no corresponding external sound exists. This often begins as an ear problem, but then becomes a brain problem (i.e. the brain is creating the perception of sound where there is no sound), so the solution to the problem often lies in tricking the brain into settling down this disordered response. Everybody's brains are different, so therapy works differently for everybody and different tips and tricks help different people. What follows are some tips and tricks that may help people with tinnitus experience some relief.

Learn triggers and avoid them

When your tinnitus is loud, reflect on recent happenings and try to identify any patterns. Certain foods have been known to increase tinnitus. Two that have been documented in the scientific literature are salt and caffeine, unfortunately! Patients have also reported their tinnitus increases after eating tomatoes, although there is no study to support this. People with tinnitus may notice it more on days when they have encountered their triggers, and knowing the explanation behind the increase in symptoms can help manage the emotional response – see point # 2 below.

Avoid emotionally reacting to your tinnitus

This is a tricky one, as the sound can be very annoying if you let it! However, the more you can avoid anger, frustration or irritation when you notice your tinnitus, the less you will notice your tinnitus. If you feel yourself getting irritated, try distracting yourself, singing, humming, thinking of something fun and positive, guided meditations, anything you can do to break down those neural associations that cause you to perceive your tinnitus as louder. The latest research about tinnitus talks about teaching patients the difference between the “presence” of your tinnitus versus the “noticeability” of the sound. While you have no control over the former, you have a lot of control over the latter, and knowing this can bring peace of mind.

Use masking noise.

If the brain is creating a disordered perception of sound, using sound in a specific, therapeutic way can help fix the mis-firing hearing area. Listening to sounds that are similar to the tinnitus but more pleasant and easy to ignore/tune out, can trick the brain into tuning out the disordered tinnitus response. Some people report relief from something as simple as using a fan while they sleep. Many hearing aids also offer tinnitus masking noise options. There are also free apps for those who enjoy computers and/or smart phones, that play pleasant sounds into earbuds to help mask the tinnitus. There is a trick to using masking noise. It must be tuned to the *same volume* as your tinnitus, so that you can just barely hear both sounds together. Listen to masking sounds on

Managing Tinnitus: Tips and Tricks

a daily basis (for example, in the 15-30 minutes before bed every night) can bring relief over time, especially when combined with other techniques.

Try everything!

Because everybody's brains are different, different solutions will work for different people. If you see a YouTube video that promises relief, or perhaps hear of a herbal remedy that might be effective, as long as it's harmless to try, give it a shot! The placebo effect (getting benefit from a treatment simply because you believe it works) can be very effective when dealing with brain disorders, tinnitus included.

In summary, because persistent tinnitus is a disorder of the central nervous system, the solution for relief lies within being creative and finding what solutions work for you as an individual. Try these techniques, place great faith in the placebo effect, open your mind to the possibility that you will experience relief, and look forward to a reduction in your tinnitus symptoms over time.

Nerissa Davies who is a registered audiologist in the Comox Valley on Vancouver Island in BC spoke at the recent Courtenay Nanaimo Group Chapter meeting. She has a master's degree in Audiology and Speech Sciences, and an undergraduate degree in Linguistics. She began her career in pediatric audiology, and now enjoys providing care for adults at the Costco Hearing Aid Centre in Courtenay. Nerissa is passionate about providing holistic care that improves hearing in ways that go beyond just hearing devices.

Severity and Treatment of Tinnitus in Acoustic Neuromas

There is a high prevalence of tinnitus in individuals with acoustic neuromas which has been corroborated by the results of research by the British Acoustic Neuroma Association. A study surveying 143 participants was conducted by the University of California, San Francisco to address two questions:

- How bothersome is tinnitus experienced by treated acoustic neuroma patients?
- Does the choice of treatment - active intervention and observation impact tinnitus severity?

It queried demographic features, tumor size and sidedness, hearing function in each ear, type of treatment: microsurgery, stereotactic radiosurgery, fractionated therapy, or observation, and elapsed time from treatment. A Tinnitus Functional Index, which is an instrument to assess tinnitus severity. A scale of 0 to 100 point was used as follows: a) "not a problem" (0-20), b) "small problem" (21-30), c) "moderate problem" (31-40), d) "big problem" (41-60) and e) "very big problem" (61-100).

Severity and Treatment of Tinnitus in Acoustic Neuromas

Results

Tinnitus severity following treatment for acoustic neuroma was found to be independent of treatment type, tumor size, tumor sidedness, time after treatment, age, and gender. Tinnitus severity was “not a problem” in 20% of respondents, a “small problem” in 20%, a “moderate problem” in 11%, a “big problem” in 22%, and a “very big problem” in 27%.

Analysis also suggested that individuals struggle most with tinnitus intrusiveness and loss of control. The tumor ear was rated deaf to fair in 85% of respondents.

The study concludes that choice of treatment, tumor size, age, and gender have little to no bearing on severity of post-treatment tinnitus distress. Tinnitus severity does not differ among the treatment choices of open microsurgery, stereotactic radiosurgery, radiation, and observation.

Acoustic neuroma patients weighing pros and cons of various treatment choices should not use post-treatment tinnitus severity as a factor in decision-making. As nearly half of the respondents have at least a “big problem” with tinnitus, the researchers recommend an integrated acoustic neuroma management strategy that includes proactive tinnitus treatment and hearing rehabilitation of essential deafness in the tumor ear.

On the Horizon

Acoustic tumor patients with single-sided deafness (SSD) rely on a single ear to capture sound information arriving from all directions.

Recent work in cochlear implantation for the treatment of SSD in the general population points to the promise of a neurostimulation device-based solution. For the majority of acoustic neuroma where the cochlear nerve has been interrupted or severely compromise, cochlear implantation for SSD is not possible because there is no means for electrical pulses to be transmitted to the brainstem.

To overcome this problem, central auditory prostheses that bypass the cochlear nerve are being considered both to improve hearing and to reduce tinnitus. The goal is to restore full hearing capability to the tumor ear and binaural hearing without tinnitus for individuals in patients.

Dr. Norman Vincent Peale, creator of the principles of 'positive thinking'

"Formulate and stamp indelibly on your mind a mental picture of yourself as succeeding. Hold this picture tenaciously and never permit it to fade.

Your mind will seek to develop this picture!"

What an inspiring quote. We have the power to create our own mental picture of our success and to hold onto it for dear life. No one else will. Take that picture now and get busy becoming one with it !

Decision Making: Treatment Options Combination of Microsurgery and Radiosurgery for Vestibular Schwannomas

By: Dr. Jörg-Christian Tonn, Department of Neurosurgery LMU Munich, Germany



Vestibular schwannomas, previously often termed as “acoustic neuromas”, are benign lesions that can present with a multitude of symptoms: from decline of hearing or sudden hearing-loss, vertigo and tinnitus up to hemiparesis and other signs of brainstem compression. In countries with a wide spread availability of MR-imaging facilities, vestibular schwannomas are more and more diagnosed at an early stage of disease. As a consequence, most of these tumors are small and patients have only few, sometimes subtle symptoms. Especially hearing is still possible on the affected side mostly with serviceable hearing and preserved spacial resolution of hearing. Impairment of facial nerve function is rare (indeed, any sign of facial nerve deficit in small tumors is mostly suspicious of a rare case of facial schwannoma).

In times of lower indication threshold for MR-imaging, patients undergoing a MR-scan because of nonspecific symptoms like headache or migraine show up with an incidental finding of a vestibular schwannoma. Thus, developed countries now face the challenge of treating oligo-or asymptomatic patients with vestibular schwannomas under the premise of functional preservation with an acceptable benefit/risk ratio as well as benefit/cost ratio. Hence, these complex tumors need differentiated treatment concepts where preservation of function is important.

In our institution, we suggest another scan in six months time and in absence of any growth in another six months thereafter. Hence, fast growth (in the first six months) and slow growth (in the twelfth month between the first and the third scan) can be detected without risk of “too late” intervention. In absence of any growth or other tumor related symptoms, “wait and scan” may be continued on an initially annual basis. Important is the close monitoring of the auditory function: speech audiometry should be performed every six months as it is more discriminative than pure tone audiometry.

Therapy is indicated in case of either tumor growth, tumor related symptoms or compression of the brainstem. In small tumors (up to 2 cm of diameter), microsurgical removal and radiosurgery are obviously comparably effective in terms of tumor control. Regarding preservation of hearing and facial nerve function , radiosurgical series show lower morbidity than surgical series.

However in larger tumors, microsurgery is warranted. Decades ago micorosurgical removal of these tumors was associated with a consideral functional risk. Nowadays, in times of multimodal

Decision Making: Treatment Options Combination of Microsurgery and Radiosurgery for Vestibular Schwannomas

electrophysiological monitoring, functional deficits are less frequent. In large series, a preservation of serviceable hearing can be obtained in 40% of those patients which had serviceable hearing pre-op. Permanent functional deficit of the facial nerve should not exceed 5 %.

In very large tumors, risk of both hearing loss and facial nerve palsy increases considerably. Here, leaving intentionally some remnants on the affected nerves can be the solution for a very effective microsurgical removal together with functional preservation even in large tumors. According to numerous reports only 20% of these remnants show some regrowth, 80% of patients show a stable lesion lifelong. In those 20% with aggressive growth of tumor remnants, radiosurgery being applied as single shot therapy is an effective treatment option to control these remnants further on. Hence, the combination of microsurgery and radiosurgery can lead to functional preservation even in large tumors.

In cases where this concept is already agreed upon upfront, both radiosurgeon and micro neurosurgeon can jointly delineate the minimal amount of tumor removal or, vice versa, the maximal tolerable amount of tumor remnant which is suitable for subsequent radiosurgery. As a next step, these volumes are defined and segmented in the pre-operative imaging data set. The data and information is subsequently integrated into the systems used for intraoperative neuronavigation. The surgeon can now, during tumor removal, map the resection cavity with a dedicated tool. The system subtracts the resected tumor volume from the initial one and presents the remaining tumor as a virtual image. Hereby, the surgeon can calculate, delineate and visualize residual tumor during this microsurgical procedure. As a consequence, in case of an intended subtotal removal the neurosurgeon can avoid leaving a lesion behind which is still too large for single shot radiosurgery. Moreover, in the background, an online calculation is being made and setting up a potential radiation plan for the remaining tissue. Hereby, the microsurgeon can determine from this information whether his resection is already far enough to protect organs at risk in case of a subsequent irradiation. This concept being termed "adaptive hybrid surgery" can pave new avenues for a combined treatment in large vestibular schwannomas (as well as in other complex skullbase lesions).

Dr Jörg-Christian Tonn, who was ANAC's distinguished speaker from Europe at our 2016 Symposium currently serves as Chairman and Professor of Neurosurgery at the Department of Neurosurgery, Ludwig-Maximilians-University Munich, Germany. He is member of prominent international neurosurgical and neuro-oncological societies such as EANO (founding member), EANS, ASCO, SNO, AANS, CNS and the American Academy of Neurological Surgery. Dr Tonn has received many honours, prizes and awards from renowned organisations. His major clinical and research focus is surgical neuro-oncology, in particular concerning gliomas, skull-base tumors and PET imaging.

Why Some Clothes Could Pose a Safety Hazard During MRI Exams

By: Lor Davila, Revision: June 28, 2017

Due to the magnets used for the imaging, facilities state no metal is allowed on an individual where an MRI is performed. The MRI technologist typically checks before starting the MRI. However, women wearing yoga pants experienced discomfort a few minutes into the MRI and needed to have the MRI stopped. Unsure of the reason for discomfort the ladies chose to take the pants off and finish the MRI with no further issue. Later it was determined to be silver fibres in the pants.

Some fabric includes silver or metal fibres, included on clothing labeled as **Anti-Microbial**. Out for caution because of this incident, more hospitals no longer allow personal clothing during scans and require the use of gowns or other hospital clothing. Metal in clothing is common in undergarments but also possible in pants. Health professionals are warning clothes containing metal fibres can be dangerous during MRI. Putting metal into a magnet can react and heat up and cause a spark or burn.

A patient learned that the hard way during a recent MRI exam. She was getting a burning sensation so strong that she had to press the emergency button for them to stop the machine and pull her out. She told them that "I'm burning and my legs are on fire." When the yoga pants were removed, the issue was resolved.

The technologist still didn't think the problem was with the pants. However, the next day, a resident physician told her the pants have silver in the material that can cause burning during the exam. MRI technologists admit it is still fairly new.

Queen's University has a MRI Safety Questionnaire that asks patients if they are wearing clothing with silver or gold threading, like Lululemon Silverescent. This technology purports to stop odor-causing bacteria from embedding itself into the clothing.

According to Alison Matthews David, a professor at Ryerson University, silver or metal fibres can turn up in other brands. "If you see anti-microbial on the label, it means it kills microbes or bacteria, and mostly likely does that with Nano Silver technology," she said.

Professor David is currently writing a book about how clothing can cause bodily harm. She says "metal has been used for centuries in clothes but it's more common now in athletic wear. We have bacteria on our skin that causes us to smell bad and the silver kills that" and "clearly, we often have no idea what's in material."

Source: Marsden, Carey. *Global News*. "Why some clothes could pose a safety hazard during MRI exams." (July 2014) <http://globalnews.ca/news/1452176/why-some-clothes-could-pose-a-safety-hazard-during-mri-exams>

Charity Begins at Home

By: Judy Haust

Recently, ANAC has received several "In Memoriam" donations honoring one of our members, or a member's spouse who has passed away. For those donations, we are very grateful! As acoustic neuromas lie far in the outfield of public awareness, it's you -- the members of the AN community -- on whom we primarily rely to direct some of your charitable giving.



Being diagnosed with an acoustic neuroma makes one part of a rare breed -- statistically, approximately 1/100,000. In fact, this incidence could be low in that ANs are often misdiagnosed, or they remain undetected because many of the symptoms such as unilateral hearing loss, tinnitus, and balance issues can also be related to less serious ailments. The gold standard for detecting ANs is through magnetic resonance imaging (MRI) and, as we all know, MRIs are expensive and therefore not routinely ordered by physicians. Indeed, most family physicians rarely, if ever, encounter a patient with an acoustic neuroma.

Raising funds to support AN research and awareness is no easy feat, especially in today's climate where we're hearing that one in two Canadians are predicted to be diagnosed with cancer over their lifetime. A cancer diagnosis is devastating, but for someone diagnosed with an AN, it can be equally devastating not only for the individual, but for the patient's family.

Each person's experience with an acoustic neuroma is different, and treatment options depend on many factors unique to that individual. In virtually all cases, quality of life becomes the central focus when deciding on options because the reality is that, in most cases, the AN never really goes away regardless of the chosen treatment. There is so much still to be discovered about these little-known Stage 1 Brain Tumours, and ground-breaking research is going on right here in Canada.

Nevertheless, finding answers to the many remaining questions requires ongoing funding. Thank you to those who have so generously donated (and continue to donate) to date, and thank you in advance to those who plan to put ANAC on their "giving radar".

Suggesting a gift to the Acoustic Neuroma Association of Canada "in lieu of flowers" is an excellent way to help build public awareness for our cause, and coincidentally to help find a silver lining in the dark cloud that hangs over the loss of a loved one.

Judy Haust has an acoustic neuroma and is a member of ANAC's Board of Directors

Zig Ziglar, American author, salesman, and motivational speaker

"Make failure your teacher, not your undertaker."

This quote produces a humorous but also serious image in one's mind. It reminds me that I have only a short time on this earth and I can learn from my failures and move on to greater things or I can let them run me to the grave. The choice is yours for you and mine for me.



Upcoming Chapter Meetings Planned

KITCHENER—WATERLOO CHAPTER

Date: Saturday October 14, 2017—10am—12pm followed by a potluck lunch
Location: Home of Tom & Helene Horlings
 #30—50 Bryan Court, Kitchener, ON N2A 4N4
Guest Speaker: David Schroevalier a registered massage therapist, Schroevalier Therapeutics. David has experience with acoustic neuroma patients and our unique issues.
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 October 21, 2017—12 noon—3pm
Location: Atrium at Crown Isle Resort & Golf Community
 399 Clubhouse Drive, Courtenay, BC
Guest Speaker: Marilyn Sharples from Victoria will address Linear Accelerator Therapy (LINAC).
For more info: Evalyn Hrybko
 (250) 282-3269 / wehrybko@saywardvalley.net

TORONTO CHAPTER

Dates: Tuesday, September 26, 2017
 Tuesday, November 28, 2017
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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