The Connection

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The Launch of the Brain Tumour Registry of Canada

By: Suganth Suppiah, MD Resident Physician, Department of Neurosurgery, University of Toronto

The Brain Tumour Registry of Canada (BTRC) which was launched this May is a national, multi-center initiative to create an epidemiological surveillance tool of brain tumours across the country. It will facilitate the development of a pan-Canadian surveillance report similar to the Central Brain Tumour Registry of the United States (CBTRUS). The similar registries in the US allows researchers to identify evolving patterns in the incidence rates related to geographical, regional and socioeconomic differences. A Canadian-centric brain tumour registry will improve evidence-based medicine and provide critical data for improving patient care.

One of the major limitations of existing national pan-cancer registries is that benign tumours in the brain, such as acoustic neuromas and meningiomas, are not tracked. The omission of benign brain tumours provides an incomplete census on brain tumour statistics in the country. Unlike in most other organs, benign tumours that develop in the brain may lead to significant morbidity and mortality, even when successfully surgically removed. Therefore, it is imperative we track these important tumours within the country to provide accurate epidemiological data and provide government and institutions with information to help allocate health care and research funds appropriately.

Inside this issue:

The Launch of the Brain Tumour Registry of Canada

Efforts to develop a Canadian brain tumour registry began in earnest in 2007, with the government passing a private member's motion mandating the collection of all primary brain tumours. Dr. Faith Davis, a professor at the University of Alberta supported by generous funds from the Canadian Brain Tumour Foundation, has spearheaded the development of this comprehensive registry. Currently, four provincial cancer registries (British Columbia, Alberta, Manitoba and Ontario) have provided data representing 70% of the Canadian population.

The first report released in May 2019 provides a summary of the incidence of brain tumours between 2010-2015. The registry reported an average of 23.5 new brain tumours diagnosed per 100,000 population, of which 64% were benign tumours. Early data from the registry emphasizes how previously available pan-cancer tumour registries would under-represent the incidence of brain tumour registries, if only malignant tumours were recorded.

In context of the Acoustic Neuroma Association of Canada (ANAC), the development of the Brain Tumour Registry of Canada will help better understand the epidemiological profile of acoustic neuromas in Canada and identify potential gaps in care. The first report identified over 1000 cases of new acoustic neuromas being diagnosed in a span of five years. Representative epidemiological data is important to help raise awareness in the general public and lobby the government for additional resources to help specific under-recognized disease processes.

Dr. Gelareh Zadeh, who is a neurosurgeon-scientist and Co-Director of the Krembil Research Institute at the Toronto Western Hospital, University Health Network, and Chair of ANAC's Scientific Medical Affairs Committee states that "the Brain Tumour Registry of Canada will be a powerful tool for us to understand the impact of acoustic neuromas in Canada. Data gleaned from this initiative will elucidate areas within Canada that are underserviced with regard to management of acoustic neuromas and further develop Centers of Excellence with expertise in multi-modal management".

Notably, Jennifer Gouchie-Terris of Moncton, N.B., clearly demonstrates the true power of patient led advocacy and how loud their voices can resonate. After her son, Brandon Dempsey, was diagnosed with a non-malignant brain tumour in 1998, she started advocating for a national brain tumour registry. Her persistence and strength led to the initial government's private member's motion in 2007. The Brain Tumour Registry of Canada will be a great tool to amplify the voice of the Acoustic Neuroma Association of Canada and bring awareness across the country.

Dr. Suganth Suppiah is a neurosurgery resident and graduate student pursuing his PhD under the supervision of Dr. Gelareh Zadeh at the University Health Network. He has strong interest in understanding the molecular drivers of oncogenesis in peripheral nerve sheath tumours, such as acoustic neuromas. He completed his medical training at the University of Western Ontario and is in the process of completing his neurosurgery training at the University of Toronto. Ultimately, Dr. Suppiah aspires to be a surgeon-scientist who aims to uncover novel therapeutics for peripheral nerve tumours.

If You Think You're Sexy...Think Again

By: E. Judy Haust, Toronto, President of ANAC

As a small charity, it's hard to raise funds in the public realm for a... what's that you call it... an *acoustic neuroma*? Oh... and it's a tumour in your *ear*... well, no, not exactly in your ear... in your *brain*? Ah... near the brainstem... *how awful!*... but you say it's *benign*? Well, not *so* bad then, I guess... all things considered...

Sound familiar? Even if such a reaction isn't being verbalized, it's clear most people are puzzled and somewhat non-plussed when they learn about this rare form of brain tumour that's rarely life-threatening. Accordingly, without a strong personal connection, considering a donation to ANAC would never cross their radar. We're but a tiny player jockeying for limited charitable resources amongst the sexy, well-known players . . . but we don't necessarily have to be doomed to this fate forever!

The reality is that an AN is still a brain tumour and the fact that it isn't malignant doesn't imply that it can't have devastating repercussions, *sometimes lifelong*. Most people don't think about that. The recent launch of the Brain Tumour Registry of Canada now recognizes the importance of collecting data on *benign* brain tumours, where previously only cancerous tumours were recorded by provincial and territorial registries. The more exposure we have in the medical community, the more educated doctors and their patients will become about acoustic neuromas.

Many thanks to Dr. Suppiah for his enlightening submission outlining the significance of the new brain registry in Canada.

Here's one way *you* can help to spread the word and elevate ANAC's public profile: we plan to hold a country-wide ***On-line Auction***, ideally in the fall, and are calling upon you to offer item donations and/or ideas. *As our members live from coast to coast to coast, we are looking for items that can easily be mailed out to successful bidders.*

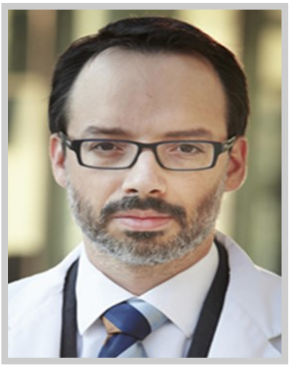
Please canvas your family, friends and neighbourhood establishments for donations of items such as tickets for professional league games, gift certificates for retail purchases: flower arrangements, cookie grams, mani-pedis, restaurant chains, big box stores, or perhaps a weekend vacation at someone's holiday venue... the list goes on. Bidders would bid only on what makes sense for them, so location-specific donations in major centres are still useful. ***Please send any ideas and/or items to be auctioned to our Executive Director, Carole Humphries, before August 31st.***

With your help, we can raise our public profile, expand our Chapter Network, and continue to support our membership long into the future. ***We look forward to hearing from you!***

Thank you and best wishes for a wonderful summer.

Answers to Your Questions About Radiation

By: Dr. David Roberge, FRCSC; CHUM



David Roberge, head of radiation oncology, works in a new "superhospital" in downtown Montreal -- the "CHUM" or "Centre Hospitalier de l'Université de Montréal". He has been performing radiosurgery for more than 15 years. Dr. Roberge currently treats patients using the latest version of the "Cyberknife" (since it installed the first Canadian Cyberknife in 2009, this is CHUM's third iteration of this robotic device) and works with a team including a neurosurgeon, ENT surgeon, neuro-radiologists and audiologists. He gives us his opinion regarding five common questions about acoustic neuroma radiation treatments.

1. **Once a patient has chosen to defer treatment, what should trigger the decision to proceed with radiation?**

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As with many decisions in the management of acoustic neuromas, the answer is "it depends". The decision can be different for each patient — taking into account the size of the tumour, the age and general health condition of the patient, and the patient's symptoms, goals and preferences.

In general, triggers for treatment can be tumour growth or new/ progressive symptoms. The dilemma will often be similar to the dilemma faced at the time of diagnosis — should I have treatment now or should I wait? On one hand, long-term outcomes (especially hearing) will be best in those patients with good cranial nerve function at the time of treatment (injury caused by the tumour during observation will often be permanent) but on the other hand, treatment itself can cause injury to the cranial nerves.

The rare circumstances where treatment "must" be performed are those where the tumour is causing symptoms by compression of the brainstem or there is a blockage of outflow of cerebrospinal fluid (hydrocephalus). Treatment should also strongly be considered for tumours with rapid growth.

In my practice, I find it useful to take the time to decide up front what the trigger for treatment will be. This will decrease anxiety at each subsequent MRI. Those triggers can be a growth rate (more than 2mm/year), a size (2cm) or a decrease in hearing.

Answers to Your Questions About Radiation

2. When is radiation not a viable option?

There may be reasons related to the tumour or the patient who favors surgery over radiation. Size used to be an important consideration but, as years go by, the evidence for the safety of radiation to treat larger tumours is accumulating. Each clinic will have a different comfort level in treating tumours greater than 3 or even 4 cm with radiation. Independent of exact size, when the goal is to relieve pressure on brain structures or restore flow of cerebrospinal fluid, radiation is not the appropriate treatment.

There are occasional cases where, even for a trained neuro-radiologist, the diagnosis of acoustic neuroma is uncertain. In these cases, it may be best to perform surgery to treat the tumour and confirm the diagnosis.

There are diseases and genetic profiles which make an individual more sensitive to radiation. Luckily these are rare and those syndromes which lead to the highest risk of radiation injury (Ataxia Telangiectasia, Fanconi Anemia, or Nijmegen Breakage Syndrome) have other manifestations which should bring them to attention. It is important for the medical team to review the entire medical history, including apparently unrelated conditions, prior to recommending radiation. There is a budding industry of tests which purport to quantify radiation sensitivity, but these are almost never used and are probably better suited to situations where more of the body would receive radiation (such as the treatment of breast or prostate cancer). It is normal to be more reluctant to use radiation in children as they will have more years ahead of them to develop radiation-induced tumours. This will be weighed in the decision but as the absolute risk of a radiation-induced tumour will remain very small, radiosurgery can still be considered for children.

There are fewer and fewer patients who cannot undergo MRI imaging as most surgical material is now made to be MRI safe and protocols are developed to allow imaging of patients with many types of pacemakers. I also find that patients suffering from claustrophobia can almost always undergo MRI on new devices with larger bore sizes — sometimes with medication or psychological support. In extreme cases, sedation by an anesthetist can be a last resort. There do remain cases in which MRI cannot be safely obtained. In those cases, radiotherapy can still be performed but will not be ideal as targeting will be done with less precise CT imaging.

3. Under what conditions is it possible to repeat radiation?

The risks of radiation will be greater when it is repeated, and the efficacy will likely be less. As the doses of radiation used for acoustic neuroma are modest, it is often safe to repeat treatment once. Although time does allow for repair of radiation damage to normal brain, this repair is never complete, and the radiation doses will be additive.

Answers to Your Questions About Radiation

The main concern when contemplating a second radiation treatment is so called "pseudoprogression". It is common for a tumour to enlarge and then shrink on its own in the first years after radiation. Because of this, it almost never makes sense to radiate again in the first 2-3 years after an initial radiation treatment.

4. When is radiation done following surgery?

Tumours are not always completely removed at surgery. Sometimes this is intentional in order to preserve nerve function. The indication and timing of radiation after surgery will depend on several factors including how much tumour is left, what nerve function remains after surgery and how fast the tumour was growing prior to surgery. It is my personal preference to let the patient recover a few months and offer radiation up-front when the tumour was rapidly growing prior to surgery but wait until the first sign of regrowth for most other patients.

5. Are there any statistics about the demographics of patients undergoing radiation?

As the Canadian Cancer Registry has not included benign brain tumours, it is difficult to have good data in Canada. In the US, the most significant demographic factor in predicting whether or not a patient had radiation for an acoustic neuroma was where that patient lived. You were most likely to have radiation if you lived in New Mexico and tenfold less likely to have radiation if you lived in Utah. I would not be surprised if we found significant analogous regional difference in Canada.

***Dr. David Roberge is a full professor in the division of Radiology/Radiation-oncology/Nuclear Medicine at the University of Montreal. Dr. Roberge is also** editor of the journal of the Canadian Association of Radiation Oncology and reviews manuscripts for more than 25 journals. More recently, he has focused on technology in radiation oncology with an interest in advanced CT imaging.*

CHUM radiation oncology has positioned itself as a leader in the theoretical and clinical investigation of dual energy CT imaging in radiation treatment planning due to his leadership. Dr. Roberge's vision is to develop at CHUM new treatment paradigms and optimal implementations of modern radiotherapy technologies.

Credit to @Adrien Williams

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.

To Judy: A Letter with a Purpose
Further Insights in the Conservative Management of a Vestibular Schwannoma

Dear Judy,

I have known you for many years personally but became your treating physician when you were diagnosed on a MRI scan to have a vestibular schwannoma (VS). I can only imagine what went through your mind when you found you had a benign brain tumour that was responsible for your left sided hearing loss. You seemed somewhat surprised I didn't more forcibly recommend an active treatment option at the time such as stereotactic radiation or microsurgical removal. I know that this is what I may have thought if I was in your position. Instead I recommended that as your tumour was relatively small, we could continue to watch it with serial intracranial MRI scans. If there was no significant growth, we could continue with this management. If your tumour did grow however then some form of active intervention would be required. Since we met to professionally discuss your management it has now been almost 6 years and I am pleased to report that everything has been stable with regard to the tumour size.

As you know we have had quite considerable experience watching individuals with VS's over the years with Conservative Management (or the Wait and Scan Approach). While we still don't know why some tumours grow and others do not (in fact up to 15% might decrease in size naturally) we certainly know that your quality of life is best if no active intervention is required as we are still not able to improve upon your lost hearing or the balance function despite our best intentions. As they say, sometimes less is better in medicine.

When we met I advised you that our 10 year longitudinal prospective study in patients (average age of 58 years at entry) with tumours < 1.5 cm in size within the cerebellopontine (CP) angle had demonstrated the vast majority of tumours continued to grow slowly (92% < 2mm/year in cross sectional diameter), the average growth rates of tumours within the internal auditory canal was remarkably 0mm/year (the presence of a tumour localized to the IAC seemed to demonstrate indolent behavior for the most part in this age group) and that 95% of patients with IAC tumours did not require active intervention. The most important stats from this study were that over 10 years 60% of patients did not go on to receive active treatment and in the 40% that did there was no harm by waiting compared to our normal surgical and stereotactic radiation controls. Moreover, a tumour usually declared whether it was growing within a five-year timeframe.[1]

Just wanted to let you know we have continued to offer a trial of conservative management to most patients with vestibular schwannomas < 2cm in size within the CP angle taking into account age, presence of other health co-morbidities and whether hearing is serviceable (and associated

To Judy: A Letter with a Purpose
Further Insights in the Conservative Management of a Vestibular Schwannoma

with favorable prognostic findings for hearing preservation surgery). Our findings have paralleled further studies regarding the conservative management of VS's from the UK, Denmark, Netherlands, US and even China specifically. [2,3,4]

I don't know whether I ever told you the story that in April 2005, I had presented our then seven-year longitudinal findings at the time to the North American Skull Base Society who were meeting in Toronto. The findings are captured in the editorial I wrote shortly afterwards for the journal, Clinical Otolaryngology, entitled "What Would You Do if You Had a Small Vestibular Schwannoma? An Apocryphal Tale." [5] I had presented the case of an intracanalicular VS in someone who was 50 years old (my age at the time) where hearing preservation was not an issue. I polled the audience to see what they would recommend as the treatment before my lecture began. Most were surgeons and it came to no surprise that almost all recommended microsurgical removal although there were a few who felt stereotactic treatment was reasonable. Only a couple of people in the audience raised their hands to show support (myself included) for an initial trial of conservative management at the time. After presenting our seven-year results (70% continued to be managed conservatively; 30% had required some form of active treatment) I asked the same question showing the same imaging study but said *"this time the patient is you".* Remarkably well over 90 % of the audience now seemed comfortable following their tumour with serial imaging initially. Interesting how things can change?

In my further review for this letter I have also looked again at the world literature and find that the conservative management option continues to be recommended certainly in the Northern European countries and less grudgingly now in the US. Unintended benefits from conservative management also interestingly demonstrated what seemed to be a significant cost saving for publicly funded health care systems (i.e., Canada) where the money saved could be reinvested in other programs. From our calculations it would take up to an 80% failure rate before the upfront costs of conservative management would exceed those of microsurgical removal for example.[6]

While not everyone should be considered a candidate for a trial of conservative management, I think that when your tumour is relatively small and hearing preservation not of concern then this option should at least be considered. The *sine qua non* however is that you need to be followed with interval scans possibly for many years to come.

When I look back, I think the advice I gave you at the time was right advice for the moment. I hope that things will continue as they have and perhaps maybe your tumour will start to get a little smaller as the years go by.

To Judy: A Letter with a Purpose
Further Insights in the Conservative Management of a Vestibular Schwannoma

Will have my office make the arrangements for your next MRI in August-September 2019. Wishing you the very best as always.

Sincerely,
John

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Dr. John Rutka is a fellow of Royal College of Physicians and Surgeons of Canada and a professor of Otolaryngology-Head and Neck Surgery at the University of Toronto. His active staff appointment is at the University Health Network where he has a subspecialty interest in otology/neurotology. He is on consultant staff at Sinai Health Systems, St Michael's Hospital, the Dryden District Regional Health Centre and the Meno Ya Win, Sioux Lookout District Hospital.

Dr. Rutka has been involved in the active management of patients with VS's over the past three decades in conjunction with his neurosurgical and radiation colleagues at the University Health Network. John has been recognized for his work and has been awarded the Sir William Osler Clinician Scientist Award previously.

Dr. Rutka is the chief mentor for the the Peter and Melanie Munk Foundation Fellowship in Otology/Neurotology and is the co-director of the UHN Center for Advanced Hearing and Balance Testing and the Hertz Multidisciplinary Neurotology Clinic. Dr. Rutka lives in Toronto with his wife Marilena.

Judy Haust and Dr. John Rutka

Judy's Response to Dr. John Rutka

Dear Dr. Rutka,

John, you are noted amongst your colleagues for the comprehensive letters you send to your patients, painstakingly explaining their diagnoses and the various treatment options available to them. I was so grateful to receive one of those letters going on six years ago! At my follow up appointment with you in early 2014 to discuss the initial MRI results, you pointed out that *the good news* was that my tumour was *benign* (the detected mass in my brain being *the bad news*!) and what a huge relief that was for me! Also, because my tumour was relatively small, I considered myself fortunate to have options in terms of which treatment to choose.

Nevertheless, as many AN patients in this dubious position soon realize, having options is somewhat akin to *sitting under the legendary Sword of Damocles* (to borrow a metaphor used by your fellow UHN neurosurgeon, Dr. Michael Tymianski, at the 2016 ANAC Symposium): *with our great fortune comes great responsibility and risk!* Regardless of which option we choose, we are never guaranteed a positive outcome, nor will our quality of life necessarily improve. As you mentioned in your recent letter to me, "Sometimes less is better in medicine."

Navigating the world of Acoustic Neuromas is an on-going journey of discovery. In the early stages, I felt very much like a pinball bouncing from one so-called "no brainer" decision to another... first choosing the translabyrinthine approach, then retrosigmoid approach and, eventually, Gamma Knife. (You may remember that I wrote my full story within an article entitled, *June Kudos*, in the Summer 2016 ANAC newsletter.) As you know, during the first two years after diagnosis, my tumour grew quite rapidly by approximately one centimetre (.5 x 1.1 to 2.1 x 1.4). To avoid having my tumour make the decision for me if it were to grow much larger, I finally decided on Gamma Knife surgery and was booked for an appointment at TWH at the end of June 2016. Miraculously, the planning MRI just prior to that surgery showed that the tumour had stopped growing! Upon my asking if a reprieve would be possible, you granted me a "stay of execution", so long I was comfortable with that decision. *Is a banana bent?* My radiosurgery was cancelled, and I felt as if an elephant had suddenly stepped off my chest! Since that time, my tumour has been stable, as determined by the semi-annual MRI scans you order. I can't help but think of the proverb, "Good things come to those who wait." Obviously, this approach isn't for everyone but, so far, patience has worked well for me.

Your recent letter reinforces this resolve to continue to embrace the Wait and Scan approach of conservative management. Who knew that my rapidly growing tumour would stop growing two years later! I'd forgotten your story from April 2005 at the North American Skull Base Society meeting in Toronto where, at the beginning of your presentation, you polled the (mostly) surgeons about what they would recommend for patients with small ANs... traditional surgery, of course, according to the majority. Then, after presenting them with the (then) seven- year

Judy's Response to Dr. John Rutka

longitudinal findings of your ten-year prospective study of patients presenting with small tumours, you polled them again, saying "this time the patient is you". Fascinating outcome! That story warrants repeated telling.

When I learned several years ago that you sat on ANAC's Medical Advisory Committee, I delved further into what the association had to offer, soon becoming a member and attending the amazingly helpful June 2016 ANAC Symposium. I also started participating in the invaluable Toronto Chapter group support meetings. It wasn't long before I decided to become even more actively involved by accepting an invitation to join ANAC's Board of Directors. I've never looked back and continue to be so appreciative of your guidance and care. I look forward to continuing this journey of discovery together!

Respectfully, and with many thanks,

Judy

Pat Greenwell's Acoustic Neuroma Diary

By: Pat Greenwell, Powell River, BC

21 years ago, 1997: Life became complicated in rural Alberta...

Treatment for breast cancer and an increasing dizziness and loss of hearing in the right ear. Doctors blamed the chemo. We've all been there. Months of trying to convince doctors that the symptoms are not imaginary. No, trust me, Doctor, antibiotics, decongestants, anti-vertigos and valium don't work.

Finally, a casual mention of dizziness to my breast cancer surgeon, dear Dr. Fraser, in Edmonton, who sent me off for an emergency CT scan and finally, within an hour, a diagnosis of a 3 cm brain tumour – an acoustic neuroma.

Shock for us both, especially my husband Ken, but I'd kind of suspected. The tumour had blocked the flow of fluid out of the brain so, in addition, I had hydrocephalus. An emergency procedure to install a Ventricular-peritoneal shunt was done the next day to prevent a stroke or aneurysm. Thank you, Dr. Max Findlay.

Now what?

I read everything I could on what my choices were, learned to live without driving, learned to live with worsening symptoms, wore a medic alert bracelet so that the shunt which goes to the abdomen doesn't get interfered with... tumour is too large to consider anything but surgery.

Pat Greenwell's Acoustic Neuroma Diary

Okay, Dr. Findlay, pretend I'm your mother, what do you recommend? Edmonton, a higher chance of facial paralysis (21 years ago) vs Toronto, Dr. Findlay's mentor, Dr. Charles Tator.

No contest.

Off to Toronto for three weeks...

Appointments arranged by Dr. Tator's secretary, Maria Vespa, giving info about hotels and transportation between hospitals for Ken and me, two traumatized people. A week of appointments and tests with Dr. Rutka (ENT) to see if I had salvageable hearing in the right ear.

Nope.

Oct 6, 1997...

14 hours of surgery at Toronto Western Hospital in the midst of a nursing shortage. I was warned in ICU to keep a bedpan handy because calling a nurse would not often work. My roommate was a teenage girl who had had numerous brain surgeries and her mom slept on the floor by her bed —a cozy threesome. Ken stayed close, took care of me, taught me to walk again when I was wobbly. A constant stream of young doctors all who had been inside my brain, learning at the hands of the master, my hero, Dr Tator.

A week of recovery, then back to Alberta. Bald, clumsy, hard to see with an eyepatch... not answering the door... Two weeks of temporary facial paralysis which felt like a lifetime. Running to the mirror every morning to see if I can smile yet and to see if my eye will close by itself. Pins and needles on my face and the traumatized facial nerves recovered.

Lots of naps, lots of hovering family, friends taking me for walks and I finally became myself again.

2019: fast forward to age 76…...

Retirement to Powell River on the BC coast in 2005.

Daily bike rides with hubby, singing in a local choir, volunteering, good health most of the time. I still find it hard to walk in a straight line, and don't balance well on one leg. Teary right eye and runny nose -- a minor inconvenience handled with tissues.

I take very good care of my left ear, try to avoid loud places and crowded events, and wear an earring from ANAC in my right ear which says, "out of order". (The grandkids love that!) We are bird watchers and while I don't know what direction the song is coming from, I can still love the song.

Gratitude is part of my life! Life is good!

How Tinnitus Can Be Effectively Managed

The James Lind Alliance Tinnitus Priority Setting Partnership, 2012

The British Tinnitus Association commissioned The Ear Foundation to investigate people's experiences with tinnitus and severe/profound hearing loss. Their report presented the views of over 1,400 people with varying degrees of hearing loss on the treatment they received, what was effective, and their hopes for the future. Forty-four per cent of those with severe/profound hearing loss classed tinnitus as a severe problem. This impacted on stress, relationships, concentration and attention, and sleep. Those with severe/profound hearing loss had the greatest impact from tinnitus but were less likely to receive help and more likely to be discharged. For those receiving professional care, it was reported that professional advice may be insensitive – for example, suggestions to use maskers or sound therapy – with the concentration being on the hearing loss and not the tinnitus.

Twenty-three people who had received a cochlear implant for hearing loss in one ear in the previous three to ten years were interviewed and completed standard Tinnitus Questionnaires. All patients switched on their implants on waking and used them throughout the day. Seventy per cent said that their tinnitus level decreased within one minute of switching them on. Scores from the questionnaires showed improvement in tinnitus typically began three months after implantation and then remained stable. This is not a rigorous experimental study, but the results are encouraging.

Several studies have explored the benefit of cochlear implantation in people with severely impaired hearing in one ear and moderate to normal hearing in the other (single-sided deafness). Arts *et al* investigated whether an implant that was programmed to deliver tinnitus suppressing sounds would have greater benefit than a standard algorithm optimised for speech perception. Tinnitus reduced in both cases, with no difference between.

Dr. Phil McGraw, popular television show host, consultant, and psychologist clearly states:

"Goals are dreams with a timeline and accountability."

It's one thing to dream of what you want to accomplish, but without a timeline and accountability your goal will remain in a dream state. But add the two essentials Dr. Phil emphasizes and your dream will become reality. And that is what this new **Brain Tumour Registry of Canada** initiative is all about.
As Dr. Phil loves to say, "How's that workin' for ya?"

Acoustic Neuroma Research Abstracts

PubMed.*gov*

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

Neurosurgery. 2016 Apr;78(4):521-30. doi: 10.1227/NEU.0000000000001154.

Safety and Efficacy of Gamma Knife Radiosurgery for the Management of Koos Grade 4 Vestibular Schwannomas.

Iorio-Morin C[1], AlSubaie F, Mathieu D.

*Neurosurgery Division, Université de Sherbrooke, Centre Hospitalier Universitaire de Sherbrooke, Centre de Recherche du CHUS, Sherbrooke, Quebec, Canada; ‡Saudi National Neuroscience Institute, Riyadh, Saudi Arabia.

Background: Gamma Knife radiosurgery (GKRS) is commonly used in treating small vestibular schwannomas; however, its use for larger vestibular schwannomas is still controversial.

Objective: To assess the long-term safety and efficacy of treating eligible Koos grade 4 vestibular schwannomas with GKRS.

Method: We conducted a single-center, retrospective evaluation of patient undergoing GKRS for Koos grade 4 vestibular schwannomas. We evaluated clinical, imaging, and treatment characteristics and assessed treatment outcome. Inclusion criteria were tumour size of ≥4 cm and follow-up of at least 6 months. Patients with neurofibromatosis type 2 were excluded. Primary outcomes measured were tumour control rate, hearing and facial function preservation rate, and complications. All possible factors were analyzed to assess clinical significance.

Result: Sixty-eight patients met inclusion criteria. Median follow-up was 47 months (range, 6 to 125 months). Baseline hearing was serviceable in 60. Actuarial tumour control rates were 95% and 92% at 2 and 10 years, respectively. Actuarial serviceable hearing preservation rates were 89% and 49% at 2 and 5 years, respectively. Facial nerve preservation was 100%. Clinical complications included balance disturbance (11%), facial pain (10%), facial numbness (5%), and tinnitus (10%). Most complications were mild and transient. Hydrocephalus occurred in 3 patients, requiring ventriculoperitoneal shunt insertion. Larger tumour size was significantly associated with persisting symptoms post-treatment.

Conclusion: Patients with Koos grade 4 vestibular schwannomas and minimal symptoms can be treated safely and effectively with GKRS.

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Acoustic Neuroma Research Abstracts

Clin Otolaryngol. 2017 Feb;42(1):92-97. doi: 10.1111/coa.12670. Epub 2016 May 26

The behaviour of residual tumour after the intentional incomplete excision of a vestibular schwannoma: is it such a bad thing to leave some behind?

Syed MI[1], Wolf A[2], Ilan O[2], Hughes CO[2], Chung J[2], Tymianski M[3], Pothier DD[2], Rutka JA[2].

Objective: To evaluate the biological behaviour of tumour remnants intentionally left in the surgical bed following the incomplete excision of vestibular schwannomas (VS) and to review the relation between extent of resection and preservation of facial nerve function.

Method: A retrospective chart review of 450 patients who underwent surgery for resection of VS over 23 years (1992-2014). Of these, 50 (11%) patients had residual tumour intentionally left on/around the facial nerve (near-total or subtotal excision) to preserve facial nerve function intra-operatively. The growth of residual tumour was evaluated using serial magnetic resonance imaging scanning; pre- and postoperative facial nerve function was assessed using the House-Brackmann grading scale.

Setting: Tertiary referral neurotology unit.

Result: Of the 42 non-NF2 cases where the tumour was intentionally incompletely excised, 28 (67%) patients underwent subtotal resection (mean follow-up 68.5 ± 39.0 months) and 14 (33%) underwent near-total resection (mean follow-up 72.9 ± 48.3 months). Three patients (all in subtotal resection group) showed regrowth. This was not statistically different from the near-total resection group ($\chi^2 = 0.92$, $P = 0.31$). The mean overall growth for these cases was 0.68 mm ± 0.32 mm/year. 5 (one near total, four subtotal) of the eight NF2 patients (62.5%) were excluded from our analysis. In the non-NF2 group, poor facial nerve outcomes (House-Brackmann scores of III-IV) were seen in 2/14 and V-VI in 3/14 of the near total compared with 7/25 and 4/25 respectively in the subtotal group.

Conclusion: Given that the primary surgery for the VS was only for tumours that were relatively large or grew during conservative treatment, the low rate of tumour remnant growth (7%) is reassuring. It may be appropriate to have a lower threshold for leaving tumour on the facial nerve in non-NF2 patients where complete resection may jeopardise facial nerve function.

Upcoming Chapter Meetings Planned

KITCHENER—WATERLOO CHAPTER

Date: **Saturday November 2, 2019**—10am—12pm followed by a potluck lunch
Location: Home of Tom & Helen Horlings
#30—50 Bryan Court, Kitchener, ON N2A 4N4
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 September 28, 2019**—1pm
Location: White Spot, 2299 Cliffe Ave., Courtenay, BC
For more info: Evalyn Hrybko
(250) 282-3269 / wehrybko@saywardvalley.net

TORONTO CHAPTER

Dates: **Tuesday, July 30, 2019**—6:30pm—8:30pm
Tuesday, September 24, 2019—6:30pm—8:30pm
Tuesday, November 26, 2019—6:30pm—8:30pm
Location: Canadian Hearing Society
271 Spadina Road, Toronto, ON (Parking in the rear)
For more info: Lynda Nash
lyndanash02@gmail.com
Kathryn Harrod
(905) 891-1624 / kath.harrod@live.ca

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