The Connection

Winter Edition 2021

A Publication of the Acoustic Neuroma Association of Canada

Association pour les Neurinomes Acoustiques du Canada

www.anac.ca

Inside this issue:

The Use of Monitoring Techniques during Acoustic Neuroma Surgery 1
Dry Eye Solutions and Acoustic Neuromas 5
A New App for Android Phones to Notify You of Important Sounds 7
Cohabiting with and Preparing to Evict My Acoustic Neuroma, "Frank"…but When? 8
Acoustic Neuroma Research Abstract 11
Acoustic Neuroma—40 years Post-Op Excerpt from my Memoir "Walk" 12
Upcoming Events 15

The Use of Monitoring Techniques during Acoustic Neuroma Surgery

By: Salvatore Di Maio, MD CM, FRCSC (neurosurgeon); Tamara Mijovic MD, CM, FRCSC (otolaryngologist); Diane Bouchard (medical electrophysiology technician); Paul Wieczorek MD, (anesthesiologist), Jewish General Hospital, Montreal, Quebec

The Acoustic Neuroma Association of Canada has been a great resource tool for our patients, for the support found from connecting online and in person with other patients with the same issues, and also for understanding the various considerations in making medical decisions and what different treatments actually entail from a patient perspective. One topic of interest which recently came up on one such group is how hearing and facial motor function are monitored during surgery. This is referring to Intra-operative monitoring (IOM), i.e., the various techniques used to observe and monitor neurological functions during surgery. The purpose of this article is to understand how the surgical team monitors neurological functions using IOM while patients are undergoing acoustic neuroma surgery. It's a great topic from our perspective too because it really highlights the fact that not just IOM but the whole acoustic neuroma operation is really an orchestrated feat made possible through teamwork. This is why the article is the shared perspective and contribution of the members of the surgical team, including the neurosurgeon, otolaryngologist, anesthesiologist and medical electrophysiology technician.

There is no doubt that surgery is an important treatment option for patients with acoustic neuromas, but it is also invasive and invariably there are risks involved. While a lot of the success of surgery ultimately has to do with the capacities and experience of individual surgeons, certain techniques such as IOM helps make a surgery safer and more successful. The use and technique of intra-operative monitoring is not unique to one center for the most part, and we

The Use of Monitoring Techniques during Acoustic Neuroma Surgery

would imagine that most surgeons that operate routinely on patients with acoustic neuromas would implement some version of the techniques grossly described here. Indeed, most otolaryngologists would consider this the standard of care.

For IOM, a technologist or neurophysiologist uses electrodes (tiny needles) and computers to continually assess the function of the nervous system throughout the whole surgery. For acoustic neuroma surgery, the main functions we are interested in is 1) facial nerve/motor function and 2) hearing, which are further described below, although there are several other neurological functions we can monitor (including during acoustic neuroma surgery) but that won't be touched on here. We are getting real time feedback about the state of facial and auditory nerve function, and with stimulating instruments we can use IOM to help locate certain structures (e.g., the facial nerve) which can sometimes otherwise be hard to locate visually when compressed by the tumour. When either irritation of a nerve or a decrease in its function is detected, it can the provide the surgeon with early warning and ideally enough time to respond and act accordingly before permanent injury occurs.

Facial Nerve Monitoring

Practically speaking, facial nerve monitoring involves the placement of an electrode inside a muscle of the face that is innervated by the facial nerve and records the electrical activity generated by the stimulation of that muscle. Most frequently, we place at least two electrodes in the facial muscles on the same side of the tumour: one at the level of the eye (orbicularis oculi muscle; the muscle that closes the eyelid) and one at the level of the lip (orbicularis oris muscle, which animates the mouth) as these are branches far away one from the other that happen to both provide vital facial nerve functions.

When the facial nerve is stretched by dissection, heated by the cautery or stimulated by a stimulating instrument, it creates activity that is transmitted to the muscles that it innervates and the muscle contracts. The contraction is picked up by the electrode that is connected to a monitor. Most monitors assign a sound to the contraction and a noise is generated by the machine that signals to the surgeon in real time that the facial nerve is being stimulated. We use this information together with anatomical knowledge, clinical judgement, and technical skills to remove all of the tumour safely or to leave a small remnant on the facial nerve in some cases to preserve its function.

Besides helping surgeons locate the nerve and avoid trauma, monitoring the nerve function provides prognosis on outcome after surgery. It can inform us about the integrity of the nerve and

The Use of Monitoring Techniques during Acoustic Neuroma Surgery

likelihood of function recovery. This means that so long as certain thresholds in IOM are maintained, a patient who wakes up after surgery with facial weakness will nevertheless go on to recover function over time. The data basically helps us understand if the nerve is temporarily stunned by all the surgical work but otherwise intact, versus irreversibly damaged. This is why the rate of initial facial nerve weakness after surgery is around 10-15% but permanent facial nerve paralysis is a lot rarer.

Auditory Function Monitoring

Many patients with acoustic neuromas will already have experienced hearing loss by the time the tumour is even diagnosed, and currently it is generally not possible to restore hearing function even if the tumour is removed. There are however, a proportion of patients who still have functional hearing going into surgery and in those patients, hearing preservation is an important goal.

In general, monitoring of cochlear nerve function is more challenging than facial nerve monitoring. One reason is that hearing is technically a lot harder to assess in a patient that is asleep. Another reason is that hearing not only depends on the integrity of the cochlea, the cochlear nerves and the brain pathways that analyze sound, but is also very sensitive to the fluctuations in blood supply to these structures which can occur during the surgical procedure.

The most common method of intraoperative auditory monitoring is through Auditory Brainstem Responses (ABRs). For this monitoring to work, the patient needs to have good hearing before surgery and a good ABR at baseline. Most often, the tumour has already stretched the cochlear nerve enough that we are unable to get an ABR and the monitoring is not possible. The cochlear nerve is very thin and splayed out at its entrance into the cochlea which makes it more vulnerable. This also at least partially explains why a lot of patients with acoustic neuromas present initially with a complaint of not hearing as well from one ear in the first place. The other challenge is that auditory monitoring does not provide instantaneous real-time and direct information the way facial nerve monitoring does. In auditory monitoring, there is always a lag, meaning that what is seen on the monitor is the impact from the surgical move that was done several seconds before. The window to identify and then react to problems in auditory monitoring is smaller, and so from a surgical standpoint hearing preservation rates are generally much lower than with facial nerve preservation, particularly for larger tumours.

The technique of ABR involves placing an occlusive ear phone in the ear canal at the start of surgery. This ear phone emits sounds and clicks that are transmitted through the ear canal to the

The Use of Monitoring Techniques during Acoustic Neuroma Surgery

ear drum, through the ossicles and finally to the cochlea. The cochlear nerve is stimulated by the noise and the resultant electrical activity is sent through the nerve to the brainstem and the cerebral cortex. Electrodes in the scalp collect these signals and the monitor will decipher a signature tracing (i.e., the ABR) by averaging out any other electrical noise through repetition and averaging over time. The amplitude (size) and overall timing of the ABR can tell us about the health of the cochlear nerve as well as the brainstem and brain pathways they relay to. Because the monitor depends on the average of hundreds of ABRs (albeit over very short periods of time), when changes are noted, some permanent cochlear nerve damage may already have occurred.

Anesthesia

The anesthesiologist and anesthesia team will ensure that patients are asleep and comfortable during the entire operation. Some of the standard medications that are used for anesthesia can, however, interfere with the ability of the electrophysiology technician and surgeon to appropriately monitor the nerves as described above. The anesthesiologist caring for these patients must therefore select alternative medications that will not only ensure the patient is unconscious, but minimizes interference with the intra-operative monitoring. For instance, in order for the surgical team to monitor the function of the facial nerve, the anesthesiologist must ensure that the patient’s muscles are not weak and not paralyzed. Similarly, the electrical signals in the nerves being monitored can be diminished with certain anesthetic medications, and alternatives must be selected (often in the form of intravenous anesthesia). The anesthesiologist, electrophysiology technician, and surgeon are in constant communication during the surgery to ensure good intra-operative monitoring signals are obtained, and the anesthesiologist can adjust the anesthetic regimen to help obtain good electrical signals, all while ensuring the patient is safe and asleep.

Conclusion

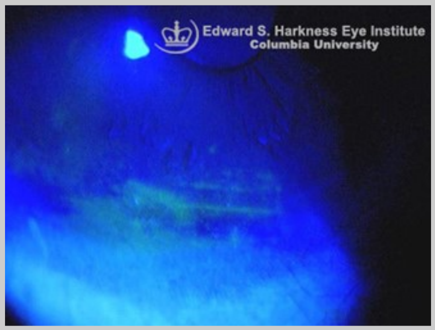
As a team, we are always looking for ways to make treatment for acoustic neuromas safer. Intra-operative monitoring is one technique we use in surgery to improve outcomes for facial and hearing nerve function. For anyone who wants to read more about this, a simple Google search for “intra-operative monitoring” and “patient information” yields plenty of well written descriptions.

Dry Eye Solutions and Acoustic Neuromas

By: Dr. Angela Di Marco OD, FAAO,
York Finch Eye Associates and Toronto Eye Care

Individuals with acoustic neuromas frequently experience eye discomfort and irritation prior to treatment but, more commonly, following resection of their acoustic neuroma. This is because the facial nerve that is responsible for closing the eye, as well as innervating the lacrimal gland which produces tears, has suffered damage, either temporarily or permanently. As such, individuals may have inadequate tear production (less commonly) and/or may be unable to fully blink and close their eye completely (more commonly) which, in turn, may result in severe corneal dryness. Complete closure of the eye is fundamental to maintain a protected and well-lubricated ocular surface. Resulting corneal dryness from incomplete eyelid closure is aptly named *exposure keratopathy*. Along with severe pain and discomfort, when left untreated, exposure keratopathy can cause permanent damage to the cornea and sometimes even vision loss.

Fortunately, there are many ways we can treat dry eye disease and exposure keratopathy associated with acoustic neuromas. Management should aim to treat the underlying cause of symptoms whether it be reduced tear production, poor lid function or a combination of both. When treatment is successful, pain and irritation can be minimized, and vision may be improved.



Corneal staining seen in green from exposure keratopathy

First line treatment of dry eye disease and exposure keratopathy secondary to acoustic neuromas often involves the frequent use of preservative free lubricating drops, gels, or ointments (anywhere from four times a day to hourly, depending on the degree of damage) as well as a lubricating overnight ointment along with tape to effectively close the eyelid before sleeping. This prevents the cornea from drying out and protects it during sleep. Moisture chamber goggles provide a similar function and are another popular treatment for both daytime and overnight use but must be fit properly to the eyes. Moisture chamber goggles are an inexpensive tool which can help to maintain moisture on the ocular surface and protect the eye from irritants such as dust, dry air, debris, pollutants etc.

Dry Eye Solutions and Acoustic Neuromas

Prescription eye drops that promote tear production, such as Restasis and Xiidra, may help certain patients who suffer from inadequate tear production due to impaired lacrimal gland innervation. Both medications take weeks to months to take effect, and can be expensive; however, oftentimes they can make a positive, non-invasive addition to one's dry eye treatment regimen. A detailed eye examination can help identify those patients who may benefit from this treatment.

Punctal occlusion with silicone plugs, or permanent occlusion with cautery, help to prevent tears from draining and thus, keep tears on the ocular surface for longer. This is another common and useful treatment of dry eye disease associated with reduced tear production and exposure keratopathy. A thorough examination of one's eyelids and one's tear production can help deduce which patients will benefit most from this treatment. If punctal plugs offer significant improvement to a patient, the punctas may be permanently closed using cautery.

In some cases, eyelid weights may also be prescribed for patients suffering from incomplete eyelid closure and exposure keratopathy. These weights may be surgically implanted or externally applied to the upper eyelid which uses gravity to assist in the closure of the upper eyelid. In turn, eyelid weights prevent dehydration of the cornea, protecting it from further complications and even loss of vision. A referral to an oculoplastic surgeon is warranted, who will assess the appropriate size and weight that is required.

Nocturnal Lagophthalmos - Scientific Figure on ResearchGate. Available from: https://www.researchgate.net/figure/External-eyelid-weight-applied-on-a-patients-upper-eyelid_fig3_246280471 [accessed 23 Oct, 2021]

Therapeutic scleral lenses are another extremely effective tool for patients with severe dry eye disease. Scleral lenses are large, hard contact lenses that sit on the sclera, or the white of the eye. These lenses are very steep and vault the corneal surface leaving the cornea untouched. They are also filled with saline solution prior to insertion. Thus, therapeutic scleral lenses are multi-purpose. They act as a bandage protecting the dry, irritated cornea from exposure to the air while the saline within the lens helps the cornea to heal and provides daylong comfort. Scleral lenses are extremely effective at reducing pain and improving vision for those experiencing severe dry eye disease and exposure keratopathy.

Dry Eye Solutions and Acoustic Neuromas

Nevertheless, scleral lenses can be expensive, and insertion and removal of the lenses may be challenging for certain individuals. However, with the right instruction and proper fit, these lenses are a viable long term daytime solution for patients with chronic corneal dryness.

Oftentimes, the treatment of dry eye disease and exposure keratopathy associated with acoustic neuromas requires more than one solution and occasionally, what may work for one may not work for another. Thus, it is imperative that a thorough history be taken, and that a detailed eye examination be conducted with your eye doctor. This will help deduce which treatment option(s) is/are most suitable for the degree of symptoms, as well as for the degree of facial nerve damage and corneal involvement.

Angela Di Marco OD, FAAO

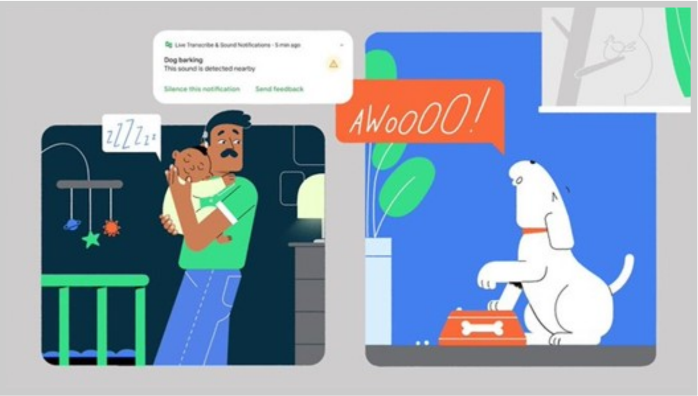
Dr. Di Marco further continued her optometric training following graduation from the New England College of Optometry in Boston by completing an Ocular Disease residency at Bascom Palmer Eye Institute in Miami, Florida, consistently ranked as the number one ophthalmology hospital in the United States. There she worked closely with world-renowned ophthalmologists serving various sub specialty clinics including ocular oncology, cornea, surgical retina, glaucoma and neuro-ophthalmology. Dr. Di Marco also ran an optometric clinic strictly serving Miami's underprivileged communities, including drug and alcohol rehabilitation programs, as well as correctional institutions.

She is the Lead Optometrist at York Finch Eye Associates and Associate Optometrist at Toronto Eye Care. She specializes in Ocular Disease including Dry Eye Disease and Myopia Control for children.

A New App for Android Phones to Notify You of Important Sounds

https://9to5google.com/2020/10/08/sound-notifications-android-accessibility/

Google has added a new accessibility app to Android, both to make Android itself more accessible and to use Android's smarts to make the world more accessible. The latest Android accessibility feature, Sound Notifications, can alert those with hearing loss to any important noises nearby.



Cohabiting with and Preparing to Evict My Acoustic Neuroma, “Frank”...but When?

By: Gavin Donatelli, Victoria, BC

Through a strange set of circumstances my acoustic neuroma (AN) was discovered in 2017. I previously worked for a youth criminal justice program offering an alternative to incarceration to help offenders get onto a positive life path. While playing an intense game of hide and seek tag, a favourite of both participants and staff, I was accidentally kicked in the head.

I suffered a concussion and, during the assessment of my injury, an MRI of my brain revealed that I had an AN on my left side. After hearing my diagnosis, I immediately recognized what they were talking about because one of my parents also has an AN. However, we do not have NF2, the genetic binomial version of an AN, and I have been told that it is pure coincidence we both have ANs based on the existing research. I have also undergone genetic testing, performed by none other than a Dr. Blood, to see if she could detect genetic markers suggesting our ANs are hereditary. The testing came back saying that no genetic mutations were identified for NF2. However, an increased susceptibility to an AN wasn’t entirely ruled out. I looked it up and, if the odds of having an AN are 1 in 100,000, then by my calculations the odds of both my parent and me having an AN are 1 in 10,000,000,000. I suspect that there just hasn’t been funding to research other hereditary causes of single-side AN.

Fortunately, when my AN was discovered, it was small (11mm x 5mm), and it didn’t seem to be causing symptoms. I was told by my ENT that I would need to go for regular MRIs to monitor the size, but it would only be life threating if I lived in a remote area far from access to advanced medical care. While my ENT mentioned surgery as an option one day, he told me that “watching and waiting” was the best course of action. I decided I needed to make peace with my tumour, which I named Frank, and hoped that we could cohabitate and share the limited space in my brain for years to come. However, Frank had other plans and he has continued grow in size.

Eventually, I arranged a consultation with Dr. Vallieres, a radiation oncologist who outlined the costs and benefits. She said that this procedure carries a lower risk of losing my hearing on the left side, at least initially, no requirement to cut the balance nerve, and would allow me to have little disruption in my life. However, given my young age of 35, there could be long-term risks of developing cancer and other issues by exposing my brain to radiation. While there are no studies showing a link between these radiation procedures and developing brain cancer, these procedures are relatively new and the majority of patients with ANs are older. Therefore, there are lower risks for them using radiation because there is less potential time for negative side effects to develop in the life span of these patients. Dr. Vallieres said that given my age, which

Cohabiting with and Preparing to Evict My Acoustic Neuroma, "Frank"…but When?

should help me recover better from the surgery, the talent of Dr. Akagami (the famed neurosurgeon in BC), and the additional risks for using radiation as a treatment, she would encourage me to consider surgery as an option. She was careful to tell me that both procedures are good choices and that ultimately, I would need to make a personal choice. I was struck by the fact that this physician was recommending a treatment option for me other than her own specialty. I really appreciated her candor and her empathetic approach to my situation.

At a subsequent consult with my ENT, my AN showed enough growth that he suggested I meet with Dr. Akagami. I saw Dr. Akagami in August of 2020. He said that both radiotherapy and surgery were viable options; however, he said the radiotherapy would provide less control of the tumour size and there is a very small risk of radiation-induced tumour growth. In addition, the radiotherapy typically provides about 15 years of control over the tumour at which point the effectiveness decreases. Since I hope to live significantly more than 15 years, this played a factor in my decision. The potential for complete loss of my hearing on my left side was more likely with surgery, but I could get lucky with a 40% chance of hearing preservation. I also understood that while there are risks to my facial nerves, chance of increased neurological deficit and other associated risks of the surgery, given my age and health, as well as the location and size of the tumour, I had a really good chance of a comprehensive recovery from the procedure. While the prospect of having brain surgery seemed daunting, I got a good feeling from Dr. Akagami and many people told me how highly skilled he is, including his ENT partner, who described his hands as "a gift from God!"

It was around this time that my mother did some research and discovered the Acoustic Neuroma Association of Canada (ANAC). Right when I really needed a lifeline, ANAC was there for me. I joined their support group and took comfort in the advice, community and collective wisdom they offered me. ANAC shared a list of top doctors I could contact for a second opinion and sent newsletters with the latest medical information. ANAC connected me with other people in similar circumstances who could share their experiences with the various treatment options, and gave me helpful tips for recovery and living with an AN. Carole Humphries, the Executive Director of ANAC, has been so kind and helpful. Carole has been a strong advocate and support for me, going above and beyond to let me know I'm not alone in this struggle.

I decided to have surgery and got my name on Dr. Akagami's waitlist in September 2020. I was told that, given my tumour size, I would likely be on the wait list for about a year before I would have my surgery. This was a long time to wait, but I mentally prepared what I like to think of as my " armour". I started exercising more, I stopped drinking, and I started doing additional

Cohabiting with and Preparing to Evict My Acoustic Neuroma, "Frank"...but When?

exercises to enhance my balance to prepare for when they cut my balance nerve on my left side to remove the AN. In the spring of 2021, I met with a new ENT who informed me that my AN hadn't grown in the latest MRI. At ANAC's AGM this past summer, I learned that tumours can potentially stop growing because they outrun their blood supply.

In May of 2021 my partner and I had been lucky enough to welcome our first child into our lives! Our son Ozzie has been such a blessing during COVID and a real inspiration to help me prepare and plan for recovery from the surgery. I did start wondering if I might be able to "watch and wait" again if my tumour had indeed stopped growing. I emailed Dr. Akagami and learned my ENT had incorrectly assessed my tumour which was in fact still growing at about the same pace. This was really hard news to take. I had been mentally preparing for surgery and the sliver of hope my tumour had stopped growing had weakened my resolve, I think in part because I'm now a parent and worried about how I will care for my son post-surgery.

My MRI in September 2021 showed that my tumour continues to grow, is 16mm by 14 mm, and I am definitely experiencing symptoms. My surgery has been postponed from September 2021 until at least the new year, because of the strain on our healthcare system caused by this pandemic. Nurses are burning out and retiring, and access to operating room time has been limited. This delay is disheartening since now I do not know when I will be able to get this tumour out of my head or if my symptoms will significantly increase before it's removed.

British Columbia, like many other places worldwide, has seen a spike in the number of COVID cases and number of unvaccinated people in ICUs during the current 4th wave. Hospitals are being pushed to the brink and are having to cancel or delay all kinds of surgeries and medical procedures. This has forced people like me to wait longer for urgent medical procedures and suffer through symptoms.

My hope is that those who are unvaccinated will listen to the advice from the consensus of global medical experts and get vaccinated to bring this pandemic to an end. At the very least, I encourage you to speak with your local health care provider about your concerns and refrain from sharing anecdotal information about COVID-19 vaccines that is unsupported by scientific evidence. My quality of life depends on people getting vaccinated so that I can access the healthcare intervention I need.

"Life is like riding a bicycle. To keep your balance, you must keep moving."
Albert Einstein

Acoustic Neuroma Research Abstract

Preservation of Hearing and Facial Nerve with Large Vestibular Schwannomas: Experience with the Retrosigmoid Approach.

Rajput MSA[1], Ahmad AN[2], Arain AA[3], Adeel M[4], Akram S[5], Awan MS[6], Bari ME[7].

Vestibular schwannomas (VS) are the most common benign neoplasms of a cerebellopontine angle (CPA), which arise from the Schwann cells of the vestibulocochlear nerve. Eighty percent of CPA tumours are VS followed by meningioma as the second common mass lesion in this critical potential space. The primary objective of the study was to assess hearing and facial nerve status before and after the surgery via the retrosigmoid approach.

Method: Twenty-seven patients from Aga Khan Hospital database between 2000 and 2007 were selected for the study. The variables included age, gender, presenting symptoms, size of the tumour, surgical approach, hearing levels, and facial nerve function. Hearing loss was categorized according to the Gardener-Robertson hearing classification and the House-Brackmann Scale was used for facial nerve assessment.

Results: Out of the 27 patients, 18 were male and nine were female. The mean age was 43 years. The most common presenting complaint in 21 patients was hearing loss and tinnitus. Headache was present in six patients, ataxia in five, and vertigo in three. Facial nerve weakness was noticed in six patients. Two patients had Grade-III paralysis, three had Grade-IV paralysis, and one had Grade-V paralysis. The audiogram confirmed the presence of sensorineural hearing loss (SNHL) in all patients. Twelve patients out of 27 had Class II hearing with the threshold between 31 and 50 decibels and a Speech Discrimination Score (SDS) of 50% to 69%. Ten patients had non-serviceable hearing and the remaining five had poor hearing. The audiogram was repeated after surgery for those 12 patients who had Class II hearing and showed that seven out of 12 patients maintained a hearing threshold within the range of Class II at the one-year follow-up (hearing preservation 58%). The facial nerve preservation rate was 56% considering House-Brackmann Grade III or less as acceptable facial nerve function.

Conclusion: The optimal treatment for small vestibular schwannomas is a matter of controversy; however, the choice of treatment for large vestibular schwannomas in patients without significant comorbidity is generally microsurgical excision. The surgical excision of a large VS with the retrosigmoid approach is found to be safe consistently. The hearing and facial nerve preservation in the study was comparable with the literature.

Charlie Chaplin, comic actor and filmmaker had this to say about the woes of life:

“Nothing is permanent in this wicked world, not even our troubles.”

Remember, “This too shall pass.” How encouraging it is to know that even in the worst of times, troubles will pass. We always have a new day tomorrow to dust ourselves off and start over again.

Acoustic Neuroma—40 years Post-Op
Excerpt from my Memoir “Walk”

By: Rosaline Christensen, Victoria, BC

My husband Casey and I were out for an evening walk when I felt a sharp pain in my left ear. The next day I made an appointment with an ENT. He said, “You could have an acoustic neuroma. Come back in six months.” I went into denial. No way! Foolishly, I didn’t go back for more than a year and when I finally got there, he confirmed his earlier suspicion that it was indeed an acoustic neuroma. He referred me to Dr. Griesdale, a neurosurgeon at St. Paul’s Hospital in Vancouver, B.C. (Dr. Griesdale passed away in 2010)

I was thirty-nine years old, stood five feet four inches tall, weighed one hundred and twenty-five pounds, had blonde hair, and hazel eyes. Some people would say my smile was infectious and that my whole face lit up when I smiled. This, changed after surgery. Instead, people looked away, or down at the ground, pretending they didn’t see my crooked face. A few asked if I’d had a stroke.

Dr. Griesdale greeted us at the door with a warm handshake and later said he too was thirty-nine years old. I had imagined a neurosurgeon as being old. Instead, his stature was youthful and sturdy, instead of grey or balding hair, it was brown, nicely cropped, and curly. He pointed with a pointer stick to the CT scan that hung on the screen behind his desk. There was a lighter image, in the shape of a golf ball, hovering above the brain. He said, “See it there? What you have is an Acoustic Neuroma. It’s about three and a half centimeters in diameter. It’s growing on the eighth cranial nerve and it touches the seventh nerve.”

He explained there were two options: one was to leave it and let it grow, the other was to surgically remove it, then he quickly added, “YOU have no choice but to opt for the surgery because you have a two-year-old daughter at home. If you let it grow, you could become incapacitated.” He said, “The surgery is lengthy and delicate, anywhere from twelve to twenty-four hours, and because they are so long I only do them on Mondays and Wednesdays. We WILL sever the eighth nerve and as a result, you will lose your hearing in the left ear. There is a fifty percent chance the seventh nerve will be damaged causing permanent facial paralysis.” I had no comprehension of the loss and change involved in having unilateral hearing and facial paralysis. He neglected to mention possible residual effects of cognitive, vestibular, and left eye damage.

Unshaken and to my later embarrassment, I asked, “Will I have to have my head shaved?”

Acoustic Neuroma—40 years Post-Op
Excerpt from my Memoir "Walk"

He said, "Yes, your head will have to be shaved, but I'll do it personally when you are under anesthetic." I replied, "Thanks, and I'd like to have it done on a Wednesday, just in case you have a weekend party." How cheeky of me!

Casey and I went down the elevator to the sidewalk, we silently walked to the car. I looked up through the tall buildings to the sky above. I felt like a tiny speck in a very big universe. We said nothing until midway home when I looked over to where he sat in the driver's seat and with tears in my eyes, I said, "I guess it's malignant." I'd never heard the word tumour unless it referred to cancer. The color drained from Casey's face, his chin quivered as he said, "I don't think so. I will give Dr. Griesdale a call in the morning and ask." It was benign.

The night before surgery, I was very nervous. Dr. Griesdale came into my room and sat at the end of my bed. He went over the procedure and reassured me he would shave my head in the morning after I was asleep. I bathed as instructed, and as I lay in bed I reached for the Bible in the bedside stand. I thumbed through the pages until I settled on a verse, Isaiah 40:31 - "They that wait upon the Lord shall renew their strength; they shall mount up with wings as eagles; they shall run, and not be weary; they shall **walk**, and not faint."

The next morning a nurse came into my room and said, "It's time." She, transferred me from my bed onto a stretcher and wheeled me to the operating room door, and left me there. I lay alone and waiting. I tightly clutched a brown washcloth to my chest like my security blanket. Soon they wheeled the stretcher under bright lights and transferred me onto the operating room table. People dressed in green were scurrying about. Someone said, "You'll feel a prick as I start the anesthetic." "Now, start counting from one to one hundred." I think I got to eleven . . .

My childhood friend Lila came to visit me in intensive care, and as always, the essence of our friendship was laughter. My left eyelid hung wide open and didn't blink. Without tear production, it was very dry and very painful. I held my hand over my eye. Lila grabbed a damp washcloth and plopped it on my eye. It kept falling off to the side, she wrapped it around my nose saying, "There, now that's putting that big nose of yours to use." We laughed.

It was October 7, 1981, I had a fifteen-and-one-half hour surgery. It was autumn, and the leaves were changing color. The landscape was changing and so was I. The lengthy surgery and long recovery left me with significant changes. It had a huge effect on me and my family. My children lost the mother as they knew her. My husband lost the wife he married. It was like a death that none of us were ready for. Grief never occurred because I was still alive.

The transformation pushed me to face the truth of an unhappy marriage. Eleven months after

Acoustic Neuroma—40 years Post-Op
Excerpt from my Memoir "Walk"

surgery, my twenty-plus-year marriage came to an end. My recovery took two years after which I took up the challenge of going to university and getting myself into the workforce as a pre-school teacher. I'd been an at-home mother for over twenty years. I could have gone back to work in the hospital where I worked before having children. The personnel officer said there was work for me, but I knew my cognitive ability was not what it was before surgery. I chose not to accept her honourable offer.

Now, forty years later I still struggle with the severe dry left eye, and visual memory loss. Frequently forgetting words and where I've left things. Keeping a writing pad near at hand, and writing things down helps. Leaving visual markers here and there is helpful. Often when I would be madly searching for an item my daughter would giggle and say, "I guess the cat took it."

When I worked with children, one day a little boy was sitting on my knee, he looked up at me and said, "Why do you wear an ear-ring in that ear when it's broken?" I immediately took that earring out. The children henceforth came to the side with the earring, the side that in children's terms, the ear that worked, my hearing ear.

A favorite quote from a favorite person of mine – M.K. Gandhi: "I do not believe India to be helpless…I do not believe myself to be a helpless creature…Strength does not come from physical capacity. It comes from an indomitable will." Yes, I had an indomitable will.

My eldest son's wise words to me were, "Mum, your willfulness needs to become willingness". Thank you, son, thus I learned to let go, let go, and let go of my willfulness, and became willing to accept my limitations along with my strengths.

If I were to offer words of inspiration they would be: Believe in yourself and the universe and keep putting one foot in front of the other even if you wobble when you **walk**.

If I were to choose a word to share it would be - 'remember'. Remember our life lessons, remember gratitude, and remember love.

"Life is our teacher. Love is the answer."

R.F.C. © February 2021

www.expressionsbyrosaline.com

Rosaline lives with her P.A.D.S. (Pacific Assistance Dog Society) hearing dog. She believes we connect through story and through story we do not feel alone. In retirement years it seems a natural progression for her to transition into writing. She hopes that writing and sharing her life story, "WALK" will give others encouragement and hope.

Upcoming Chapter Meetings Planned

KITCHENER—WATERLOO CHAPTER

Date: **Wednesday, February TBD, 2022**—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, February 2022 TBD**—10am—12noon
Location: Virtual Meeting
For more info: Evalyn Hrybko
(250) 282-3269 / wehrybko@saywardvalley.net
Caroline Bradfield
(250) 897-3553 / digitalgal@shaw.ca

TORONTO CHAPTER

Date: **Tuesday, January 25, 2022**—6:30pm—8:30pm
Tuesday, March 29, 2022—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

ANAC Board of Directors

Rebecca Raghubeer	President
Judy Haust	VP/ Past President
Adam Rochacewich	Treasurer
David Tsang	Secretary
Anna Gurdon	Director
Nicholas Kucharew	Director
Chrissie Rejman	Director
Staff	
Carole Humphries	Executive Director