The Connection

A Publication of the Acoustic Neuroma Association of Canada

Association pour les Neurinomes Acoustiques du Canada

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Summer Edition 2016

New President's Message

Hello everyone, my name is Rex Banks. I am honoured to be granted the opportunity to serve as President of the Board of Directors for the Acoustic Neuroma Association of Canada (ANAC). Before taking off though, I want to give a huge thank you to our outgoing President, Lyna Newman, who showed outstanding leadership and passion for ANAC over the past three years. Lyna paved a path and struck a course for us to follow which I am privileged to help guide along with the rest of the Board and input from all of you!

My first connection to ANAC started twelve years ago when I helped re-boot, with key volunteers, the Toronto chapter support group held at the Canadian Hearing Society. As an audiologist, I have learned so much from the ANAC members who help run the group along with the many newly diagnosed patients who have come to us over the years in search of comfort and information. Because of these experiences, I have grown exponentially as an audiologist and am eager to give back as the association's President.

Many of you recently attended our 2016 Symposium which was held in Toronto. It was chalked full of vital information no matter where one was in their journey with acoustic neuroma. Our symposium could not have been possible were it not for the leadership, the generosity and support of Dr. Gelareh Zadeh, Scientific and Medical Director of ANAC, our Medical Advisory Board and the folks at Toronto Western's BMO Education and Conference Centre.

A first for ANAC – a live webcast of the forum was made available to those unable to participate in person and individuals from across Canada and US joined in. However, as one member remarked "the trip from BC to attend was expensive but worth every penny!" It was a fantastic conference and I look forward to the next one.

Inside this issue:

New President's Message

ANAC is working on several initiatives this year. One of the most important is our website, which is in need of a complete makeover. The new website is currently under development and will offer members the ability to interact with each other, glean valuable information, and pay for memberships online. Upon completion in September, the website will have a fresh, modern appearance and architecture, adhere to accessibility standards and laws, and be optimized for use by mobile devices such as smartphones and tablets. I can't wait until it's ready and I hope you all love it!

And did I mention you'll be able to pay for your memberships online? Soon, the inconvenience of having to mail in a yearly check will be long gone. I cannot stress enough that without your memberships, ANAC could not exist. We acknowledge that joining or renewing needs to be an easy and seamless process for all.

Another big change for ANAC is the addition of Carole Humphries as our Executive Director. Carole has an abundance of energy and enthusiasm which is all focused on making ANAC stronger and sustainable into the future.

Please know that all of us on the Board are committed to ensuring that ANAC is here for years to come. We can't do it without you though and will need your help. I look forward to the next year and please don't hesitate to write to me at rbanks@chs.ca with any suggestions or ideas that you may have for ANAC.

Thank You!

Rex Banks, Au.D., Doctor of Audiology

"I was always looking outside myself for strength and confidence
but it comes from within. It is there all the time."
Anna Freud, daughter of Sigmund Freud
found that what she was looking for she had all along.

How often we spend our lives looking outside ourselves instead of looking within where the confidence and strength to accomplish our goals and desires has been from the beginning. "It is there all the time." We simply have to look in the right place, recognize it, and allow it to come forth. May we do this today and for the rest of our days.

Innovation and Trends in Acoustic Neuroma Treatment

By: Gregory P. Lekovic, M.D., PhD.

Progress in medicine is often imagined in terms of "eureka' moments, such as those popularized in Thomas Kuhn's *Structure of Scientific Revolutions.* In clinical medicine, a better analogy is a mountain climber, always trying out different handholds- abandoning most as unreliable or too fragile – before settling on the next step upward. This image captures incremental innovation in acoustic neuroma treatment.

After a new technique or other innovation is proposed or first described, a process of trial and error follows before results can be reviewed and consensus can be reached. After all, many breakthroughs that are now taken for granted – such as the use of facial nerve monitoring, radiosurgery for acoustic tumors, or even the operative microscope – were controversial when initially proposed.

I would like to share with the readership of ANAC's "Connection" one perspective on what trends—in research, diagnosis, and treatment of patients with acoustic neuroma – to watch out for in 2016 and beyond. Some of these supposed advances may turn out to be false—and may not bear the weight of our mountain climber—but others surely will one day be somehow incorporated into our standard approach to acoustic neuroma treatment.

The following comments regarding 1) diagnosis and observation, 2) treatment planning and technique, and 3) novel treatment alternatives, are by their very nature idiosyncratic and based solely on my own opinions, with the goal of stimulating discussion and creative thinking about acoustic neuroma diagnosis and treatment.

Diagnosis and Observation

The journey of any patient with acoustic neuroma necessarily starts with the diagnosis and is followed by a process of decision-making regarding whether to observe the tumor or undergo some form of treatment. This decision making process is informed by largely historical data. We need better data – both better quality (objective) statistical/population data, and personalized data applicable to individual patients – to improve the decision making process when opting to forego further observation and undergo treatment. At the same time, we should not be surprised if some assumptions we have made along the way are upended.

Objective quality of life data

I expect we will see continued research on the consequences of treatment on quality of life. For a disease that is, for most patients, not a life-threatening problem but a quality of life problem, this seems appropriate. I believe that the impact of surgery on balance problems, in particular, is emerging as an issue that needs better definition.

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Last year saw publication of data suggesting relative equality between different treatment modalities and balance outcomes, which runs counter to many institutions' experience (including our own). Since we do not yet have consensus on which patients with balance complaints, for example, would benefit from treatment, we can expect further efforts to determine which patients are likely to actually benefit from surgery with regard to balance problems.

The promise of personalized medicine

While perhaps the least likely to result in a clinically useful tool in the next year, research into "hot" topics in medicine such as biomarkers and nanoparticles will be applied to acoustic neuroma research with the goal of individualized treatment.

Biomarkers can be thought of as substances that can be detected in the blood or other body fluid that reveal the presence or behavior of a tumor or other disease. For example, certain biomarkers include markers' for cancer of the gallbladder, liver, breast, or prostate. These markers can be detected even before a tumor is large enough to be seen on CT scan or MRI. Is there a biomarker that can predict which acoustic tumors will grow, or which tumors are less likely to respond to radiosurgery? This information would obviously be of intense value to patients, especially those newly diagnosed. Tiny nanoparticles are usually defined as either naturally occurring or synthetic particles on the order of billionths of a meter in size. These could include particles in blood or spinal fluid composed of fragments of cell membrane, circulating DNA, and other constituents. Researchers may one day be able to predict tumor behavior based on a sample of blood or cerebrospinal fluid. This would provide us with an entirely new class of data with which to counsel patients — individual, personal data rather – than relying 100% on reference to the natural history data available now. This would indeed be a real change.

Treatment planning and technique

Because decision making for acoustic neuroma can be so complex, any improvement in techniques that lowers the risks or increases the odds of a good surgical outcome may tip the balance for patients making up their minds about whether and/or how to treat these tumors. For example, advances in imaging and surgical technique may reduce the risk to the facial nerve or allow for better odds of hearing preservation. Similarly, recent data has challenged the conventional wisdom that large tumors are necessarily treated surgically.

Advanced MRI imaging for surgical planning

A technique called diffusion tensor imaging or "tractography" can be used to try and predict the course of the facial nerve relative to the tumor. Unfortunately, so far the ability of diffusion images to help visualize the facial nerve has been hampered by technical constraints, such as inter -operator variability. If this technique can be refined such that it could be used for smaller tumors

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– for example in determining the course of the facial nerve relative to a small tumor in the internal auditory canal – it may provide real benefits to surgical planning.

Surgical innovations

I expect the trends towards judicious use of extensive surgical approaches, along with greater adoption of surgical endoscopes, and tailored "keyhole" approaches to continue.

The concern of many neurosurgeons has been whether or not 'minimally invasive' techniques are 'minimally risky' or 'minimally effective'. However, we are likely to see the incremental acceptance of using the surgical endoscope in surgery for acoustic neuroma, whether as the primary modality of visualization during surgery, or as an adjunct to traditional microsurgery.

Adjunct in this case means to be used in conjunction with traditional microscopic resection of tumors. For example, our early experience suggests that endoscopy may be beneficial for hearing preservation in selected patients with tumors impacted laterally in the fundus of the internal auditory canal, although it remains to be defined in what cases the endoscope provides a distinct advantage.

Radiosurgery for large tumors

Conventional wisdom has long been that patients with large acoustic tumors, usually defined as those exerting pressure or mass effect on the brainstem, are preferentially treated with surgery. Several recent reports have shown satisfactory results with radiosurgery for these patients, albeit with higher rates of complication and treatment failure than that seen for smaller tumors. These reports are largely based on a single session radiosurgical treatment plan.

An open question about large tumors undergoing radiosurgery is whether splitting the radio-surgical treatment into three or five sessions ('hypo-fractionation') compromises tumor control or minimizes treatment morbidity.

Obviously, further research is needed to better define the appropriate role of radiosurgery for large tumors, and the best technique for such treatment.

Novel treatment alternatives

Are there viable alternatives to surgery or radiosurgery for acoustic neuroma on the horizon? A new class of anti-tumor drugs called monoclonal antibodies has been responsible for great advances in the treatment of cancer, most notably for breast cancer. These agents are not chemo-therapy in the traditional sense since they use the body's immune system to fight tumors, and are generally referred to as 'immunotherapy'.

Although acoustic neuroma is a benign tumor, the immune system plays an important role in the behavior of these cells and their response to therapy. There is evidence that tumors are constantly

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at war with the body's immune system, shedding particles that can be picked up in the blood stream (see biomarkers, above) in the process. Avastin (bevacizumab) is a drug in this class and has been used for the treatment of acoustic neuroma in patients with NF2. Further research along these lines in 2016 is to be expected.

Importantly, new alternatives to radiosurgery also became more widely available in 2015 and may soon be applied to acoustic neuromas and NF2.

These laser-based treatments use surgically implanted lasers to deliver heat energy to the tumor with real-time MRI guidance. There is no ionizing radiation emitted during these procedures. However, the dispersion of heat is less well controlled and the ability to preserve hearing or protect the facial nerve from injury may be limited. I suspect that in the beginning, these treatments will be first applied to patients with NF2, perhaps including those for whom radiosurgery has already failed and/or who would be considered too high risk for surgery. As experience grows with these novel approaches to NF2 patients we will be able to better determine which if any are also applicable to patients with sporadic tumors (acoustic neuroma).

Conclusion

In spite of the promises of future breakthroughs, nothing said above changes the practical issues facing patients newly diagnosed with acoustic neuroma. Until their utility is confirmed, any of the above “innovations” may turn out to be spurious. So I would caution against relying on them for decision making.

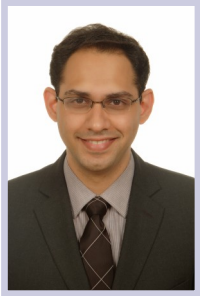
Ideally, patients should seek treatment at a high volume center, necessary not only for better surgical/radiosurgical outcomes but also because high volume centers are able to vet the many different competing ideas and technologies and confirm which is a real step forward.

To return to my mountain climber analogy, we do not know yet which of the above items might be handholds that will not bear the full weight of progress, and which we will look back on one day as obvious. We can be certain, however, that medical trends and advances will continue to move treatment of acoustic neuroma forward.

Gregory P. Lekovic, MD, PhD, is a graduate of the University of Chicago and the University of Illinois at Chicago College of Medicine. He joined the House Clinic after completing his residency and fellowship training in Skull Base Surgery and Stereotactic Radiosurgery. Dr. Lekovic whose interest in acoustic neuroma began during his PhD research in auditory neurophysiology has authored more than 50 peer-reviewed original publications.

ANAC appreciates Dr. Lekovic and ANA’s support. This article appeared in March 2016 in ANA USA’s Notes.

Quality of Life
The Essence of the Patients with Acoustic Neuromas

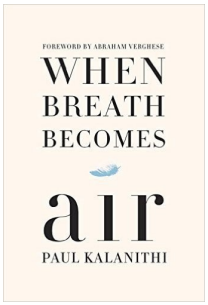


By: Dr. Mazda Turel

Quality of life (QoL) is a multidimensional concept that includes an individual's subjective evaluation of all aspects of their life – physical, mental, emotional, social and even philosophical and spiritual. The last two are my personal incorporations into the definition since this is what human beings become when faced with adversity.

Thankfully, the entity of a Vestibular Schwannoma is benign one, but unfortunately in a 'malignant' location of the head. Patients with small tumors can sometimes have exasperating tinnitus and those with larger ones, disabling ataxia. Some, with tiny tumors have the apprehensive option of watchful waiting, while others with giant masses have no choice but an operation. Surgery includes encountering vital cranial nerves, blood vessels and the brain stem in the vicinity of the tumor. If any of these vital structures are disturbed, the event can damage QoL.

QoL becomes a moving target from one individual to another and more so at different time points in people's life. It varies with age, sex, character, socio-economic status, job satisfaction, the nature of relationships and willingness to accept our situation and make the most of it.



I'd like to tell the story of Paul Kalanithi, a brilliant neurosurgeon while in his final years of residency at Stanford and fielding job offers from several major universities was suddenly diagnosed with metastatic lung cancer. In a single moment of recognition, everything he had imagined for himself and his wife evaporated, and a new future had to be imagined. For him exemplary QoL transgressed from the desire of achieving academic excellence and stepping onto center-stage, to being able to hold his newly born daughter's hand to whom he dedicated the heart wrenching story of his life, in a book titled 'When breath becomes air' - the quest of a 3-year-old on what makes life more meaningful. It's book of two halves: the first is about becoming a doctor and saving life, the second about becoming a patient and facing death. I encourage you to read it.

Fortunately, in acoustic schwannomas death is a rarity, almost never seen in in this era modern medicine. Our strategy of treatment has evolved significantly over the last 3 decades, ranging from the enthusiasm of complete removal, which is often fraught with facial disfiguration and hearing loss, to the current philosophy of tailoring the operation to such an extent so as to minimize the tumor size. The latter strategy enables preservation of these nerves, leaving the remnant behind for radiosurgery to control.

What has also evolved is patients' involvement in decision making of their care and their willingness to participate in research allowing doctors to gain a better understanding of their overall condition. Several studies have shown that the perception of outcome by the patients often

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differs from that of the physician and hence QoL studies are needed to assess the effect of treatment as defined by the patient. Answering uncomplicated questions on standardized global heath tools such as the short Form 36 (SF-36) and the Glasgow Benefit Inventory (GBI) can do this. Studying patients QoL, both before and after treatment, or even while watchful waiting gives insight into the holistic effects of observation or surgery and not just a simplified account of the 'audio-facial' morbidity that this tumor is associated with.

We conducted a prospective study in 100 patients who underwent surgery for large and giant tumors. The interesting finding was that these patients scored lower on all the QOL domains compared with the normative population. This finding was collaborated by another study which showed that the SF-36 scores of vestibular schwannoma patients at diagnosis were significantly lower compared not only with scores of healthy controls, but also with those of patients with head and neck cancer, benign prostate hypertrophy, or chronic obstructive pulmonary disease and deaf patients. Thus, it is prudent to use each patient as his or her own control to determine QOL outcome after surgery. If the normative population scores are used to determine the outcome of surgery, the benefits of surgery will be underestimated.

The results of our study showed an improvement in health related QOL compared with preoperative status in all cases, with 63%–85% of patients showing a clinically important difference in various domains at one year. A second follow-up evaluation was performed at two years and showed sustained improvement in SF-36 scores.

In conclusion, the QoL is more important than life itself. There is no passion to be found in settling for a life that is less than the one you are capable of living. Our happiness is enriched by the essence of our thoughts, so let's have positive ones. Our well-being is enhanced by the nature of our actions, so let's have kind ones. Let us fill each and every waking moment with enthusiasm, affection and gratitude. Like Abraham Lincoln once said, 'it's not the years in your life but the life on your years' that makes all the difference.

Dr. Mazda Turel who was ordained a priest in the Zoroastrian faith is a graduate in Neurosurgery from Christian Medical College in India. He was awarded the Jacob Chandy Gold Medal; a distinction conferred previously to only four other recipients in 35 years. In his pursuit of excellence, he recently completed a fellowship in skull base surgery and neuro oncology under the mentorship of Dr. Gelareh Zadeh at the Toronto Western Hospital and is currently pursuing a fellowship in complex spine surgery at Chicago's Rush University.

"It's where we go, and what we do when we get there, that tells us who we are."
Joyce Carol Oates, an American author and Pulitzer Prize nominee

This quotation goes beyond mere success and goal setting and inspires one to look a little deeper into our lives and to question who we are as individuals. We're only as successful as we are persons of integrity.

Complete Facial Palsy: Four Things You Can Do

By: Susan Rankin

When I first started treating acoustic neuroma (i.e. vestibular schwannoma) patients 30 years ago, about 50% of my clients had facial palsy as a result of microsurgery to remove an acoustic neuroma. Thanks to much better facial nerve monitoring during surgery, and other options like stereotactic radiosurgery or monitoring, I see only the occasional acoustic neuroma patient in my private practice now.

The few people I've seen recently have all reported similar outcomes post-operatively. The acoustic neuroma was successfully removed, the facial nerve was preserved and was working initially. Then, within the first few days, the affected side of the face suddenly falls.

The convention for most facial therapists is to wait until the patient starts to get movement before they begin treatment. However, I have always preferred to see people once early on. When people are sent home and told to wait for recovery, they often don't know what to do while waiting. It's not unusual that they then check out "Dr. Google", surely it will have some advice on what to do. As we all know there's good information and not so good information on the internet. I'd rather give people good information about what to do and what not to do in those early days. There are 4 things I review with people when I see them initially:

Education

Using pictures, I review the facial nerve structure and function, degrees of injury to the nerve, recovery profiles and some general time-lines for what to expect. I emphasize that no gross facial exercises should be done until the nerve and the muscles are "plugged in" on the affected side--regardless of what the internet or friends and family say. Exercising before the nerve has recovered and reconnected with the muscle will only strengthen the good side and cause more dysymmetry.

Eye Care

When the eye can't close and tearing has been affected, the eye is at risk. Patients can develop dry spots on the cornea or experience corneal damage. I usually recommend people see an Ophthalmologist who will examine the cornea and decide if protective surgery is required. Eye products should be preservative free and used frequently, not just when the eye feels dry; that's too late. Heavier ointments like *Lacrilube* and *Tear-Gel* can be used at night. I also review the use .of eye taping, protective sunglasses and manual blinking.

Improving Circulation

Because muscles are not in use, blood circulation tends to be poor. As a result it is important to maintain good circulation on the affected side. This can be done by applying moist heat for 5

Complete Facial Palsy: Four Things You Can Do

minutes, 3 to 5 times a day or by tapping the face for 20 seconds, frequently during the day.

Maintaining Symmetry

While one side is doing all the talking and making facial expressions, it becomes stronger and pulls the face to the unaffected side. The mouth and the nose are particularly prone to pulling over. A simple technique is to passively pull the mouth and nose on the strong side back towards the middle. It is called a half-circle massage and it is best done after laughing or talking a lot.

I review these four things with people who have no facial recovery after acoustic neuroma removal. Once they have that information we stay in touch to see how they recover and decide if any further therapy is required.

Susan Rankin, BScPT, MHSc is a physiotherapist practicing in North Vancouver, BC at Canopy Integrated Health. She was trained in 1986 by a therapist from Madison, Wisconsin where facial neuromuscular retraining began. For more information you can go to www.rankinphysio.com

Toronto Chapter Celebrates its 12th Anniversary

By: Lynda Nash, Toronto Chapter Co-Leader

When I was first diagnosed with an acoustic neuroma in 1999, a Toronto Chapter didn't exist. However, in 2004, Henry Kitts, an individual with an acoustic neuroma, met with Dr. Rex Banks now Director of Audiology at the Canadian Hearing Society (CHS) to discuss the need to recreate a support group in the Toronto area. The first meeting spearheaded by Rex, Joanne Bennett and myself was held in May 2004.

To raise funds, we organized two dinner/dance events with silent auctions in 2006 and 2007 and secured from my financial advisor a "door prize" and several monetary donations from RBC Dominion Securities which helped support ANAC symposiums.

I want to thank Kathryn Harrod who has been assisting me in leading the group since 2009 and everyone who has attended our meetings over the years. Without their support, and sharing research acquired and treatment experiences the chapter would not thrive. On May 31, 2016, the Toronto Chapter celebrated its 12th Anniversary. Kudos to Lyna Newman, Americo Meneguzzi, and Nick Kucharew, for paying it forward and sharing their time and skills on the board of directors. Not only have we benefitted from Rex's expertise and support for the last 12 years, Rex is now ANAC's new president!

Please support ANAC and your local support group.

Trouble Hearing?

Are you having trouble participating in the conversation? Do you often have to ask people to repeat themselves? Do you tend to withdraw from social gatherings?

If the answer is "yes", Jillian Price, Chief Audiologist of the National Campaign for Better Hearing recommends that you schedule a free, no obligation hearing assessment.

Hearing loss affects more than 10% of all Canadians, and 50% of Boomers who are over the age of 65. As a result, hearing loss is the third most prevalent chronic healthcare problem in Canada after hypertension and arthritis. Yet research shows that the average Canadian with hearing loss waits 5 to 7 years before seeking help.

"Perhaps the greatest impediment to seeking help is that hearing loss is often gradual, so most of the time a friend or relative will notice it before the individual does. In other words, a hearing loss is more noticeable to others than simply wearing a hearing aid", says Price.

"The decision to treat a hearing loss at the onset has many benefits in that one can expect a shorter and easier transition into the world of amplified sound. This is because your ears must learn how to hear forgotten sounds again, and the longer one goes without hearing them, the harder it can be to re-learn them."

The impact of hearing loss on quality of life is significant. An untreated hearing loss causes needless stress, anxiety and embarrassment. It may also lead to self-imposed isolation and even depression. While hearing loss is a permanent and irreversible condition, the good news is that most hearing loss is treatable, and the earlier it is diagnosed and treated, the easier it is to return to normal levels of communication with family, friends and co-workers.

That's why the National Campaign for Better Hearing was created – An initiative to help all Canadians over the age of 60 get a free baseline hearing test and begin annually monitoring their hearing health. In 2015, more than 200 hearing clinics donated $2.00 for every hearing test they performed in order to provide hearing aids for those who couldn't afford them. They surpassed their goal of raising over $100,000 for hearing aids, so this year they pledge to donate $4.00 for every hearing test in order to raise over $250,000!

For more information about the National Campaign for Better Hearing, or to schedule a free hearing test at a one of more than 200 participating clinics across Canada including, please call toll-free **1-888-300-8351** or visit **CampaignForBetterHearing.org/ANAC**.

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The World of Acoustic Neuroma 2016

ANAC members, individuals newly diagnosed with acoustic neuromas, neurosurgeons, otolaryngologists, resident physicians and researchers gathered together on Saturday June 4, 2016 at the new BMO Education Centre to explore the management and treatment options including how best manage long-term symptoms of acoustic neuromas.

This symposium exemplified the knowledge and skill as well as the respect that Dr. Gelareh Zadeh holds with her colleagues from around the world including the willingness of her peers from Germany and others outside Ontario to bring them together to Toronto and be an integral part of this initiative.

Communication Access Real – Time Translation (Carting) a service from the Canadian Hearing Society was used to provide close captioning for the audience with hearing loss.

This symposium would not have been possible without the Scientific and Medical Director ANAC, Dr. Zadeh's leadership. ANAC is grateful for the scientific and financial support of University Health Network Neurosurgery Associates and Dr. Michael Tymianski, Chair of Division for their support.

ANAC Appreciates Our Sponsors

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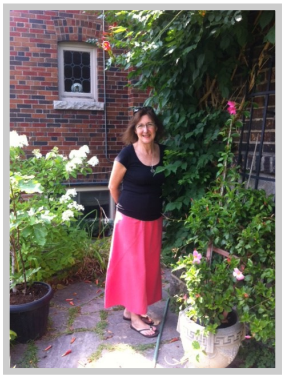
The Acoustic Neuroma Association of Canada is working to develop support groups in each province across Canada to ensure people affected by Acoustic Neuroma receive the support they need. Volunteers are currently needed in British Columbia, Quebec and all East Coast Provinces. If you are interested in helping establish a new group in an under serviced area, please contact Carole Humphries at the National Office for an information package and support.

director@anac.ca **1-800-561-2622**

June Kudos!



By: E. Judy Haust, Toronto, Ontario

I wish to express heartfelt thanks to the organizers of the 2016 ANAC Symposium, including Dr. Gelareh Zadeh and Rex Banks; as well, to all the participants who took time out of their busy lives on a Saturday to impart medical and technical expertise to an appreciative audience. The Symposium, held at TWH on June 4th, offered acoustic neuroma patients the opportunity to attend a well-rounded and highly informative full-day event.

My AN, which was diagnosed serendipitously in February 2014 after several years of mild unilateral hearing loss, slight tinnitus and occasional vertigo, had grown rapidly in the subsequent two-year period. At almost 2 cm, it had become extra-canalicular and had reached the brachium pontis, prompting my ENT to send me for consultations with two of his colleagues -- a neurosurgeon and a radiologist – to discuss treatment options in further detail. Those consultations behind me, along with two very helpful Toronto Chapter ANAC group support meetings (and far too much net-surfing), I anxiously awaited the Symposium, wondering if anything I might learn from it would alter a recent resolve to choose Gamma Knife treatment.

What a learning experience it was! I lapped up the pool of information like a parched pooch, beginning with ENT specialist, Dr. John Rutka's Natural History of Acoustic Neuromas: Its Mystery and Impact. Next, we waded through the pros and cons of microsurgery vs radiotherapy; were enlightened on the science and technology behind those treatment options; listened to a panel of multi-disciplinary specialists assess and discuss specific case studies; gained a different perspective on the human side of dealing with large ANs; acquired information on the latest hearing aid devices, as well as the benefits of vestibular physiotherapy; and, finally, heard about therapeutic targets for different types of schwannomas, and clinical trials examining the feasibility of drug therapy for benign tumours.

Dr. Jörg-Christian Tonn, chair of the Neurosurgical Clinic of the University of Munich (Grosshadern), discussed Adaptive Hybrid Surgery (not yet available in Canada), and took part in the Multidisciplinary Tumour Board Panel that deliberated over treatment options. Another highlight (among many for me) was Indian-born, Dr. Mazda Turel's presentation on Quality of Life issues pertaining to large acoustic neuromas, opening our eyes to an entirely new perspective on facial paralysis, a surgical risk most of us in Western society dread. Upon Dr. Turel's recommendation to everyone, I have since read *When Breath Becomes Air*, and successfully proposed it for my book club's 2016/17 reading list. Published in January of this year, it was written by (the late) Paul Kalanithi, a brilliant young neurosurgeon, who was diagnosed with terminal cancer in the final year of his graduate studies, suddenly becoming the patient instead of

June Kudos!

the doctor. As his illness progressed, he turned to writing, a long-neglected passion. Each one of us can benefit from Paul's insight and profound glimpses into what can make life meaningful in the face of imminent death. The forward, written by Abraham Verghese, and the epilogue, written by Paul's wife, Lucy, fittingly encapsulate this beautiful and moving memoir.

Unlike the challenges of being faced with a malignancy, such a Paul's, having an Acoustic Neuroma is a mixed blessing. Yes, it's a benign brain tumour but, in most cases, the patient is left to choose from a "menu" of possible treatment options, all equally unappetizing. It would be so much easier to have a doctor tell us what to do! UHN neurosurgeon, Dr. Michael Tymianski pointed out that ANs generally "become life-threatening only when you start fiddling with them." He compared our predicament as AN patients to sitting under the Sword of Damocles: regardless of which treatment option we choose, we are not guaranteed a positive outcome, nor will our quality of life necessarily improve. This rang true for me as I've been relatively asymptomatic. If I were to choose translabyrinthine surgery, the most direct approach to the tumour, I would be left with unilateral deafness; if retrosigmoid, which involves cerebellar retraction, I would likely be faced with only partial removal and possible (although unlikely) facial paralysis; if Gamma Knife radiosurgery, I would go home feeling apprehensive about delayed side effects . . . and then, of course, there's that thorny issue of the head frame!

Through information gleaned from the Symposium, I now better understand why lifestyle and personality play such a significant role in deciding on treatment, and why the doctors can provide us only with options, not directives. There are no clear-cut choices: acoustic neuromas remain rare, and randomly-assigned studies are not available to help us out as the treatments are all so different based on how each individual patient's AN presents.

In my case, at age 63 (shh, our secret!), concerns over cerebellar retraction and potential ill effects from anesthesia eventually steered me away from my original resolve to choose microsurgery. Following the Symposium, I was more at peace with the decision to go ahead with less invasive radiotherapy – a good thing, as my Gamma Knife appointment had been booked for June 28th. However, miracle of miracles, the planning MRI showed no further growth and I was offered a "stay of execution"! The tremendous sense of relief I felt truly took me by surprise. Once again embracing the "Wait and Scan" option, I could look forward to a summer visit from the grandkids with a light heart. Nevertheless, when intervention becomes imperative, I will put my faith in the top-notch UHN medical personnel and face GK with confidence . . . if not still with a touch of trepidation!

Kudos to ANAC for all the hard work that goes into supporting AN patients and their families through chapter meetings, newsletters and special programs such as the 2016 Symposium!

Evalyn Hrybko's Story

By: Evalyn Hrybko, BC Chapter Leader

I am now almost 47 years' post-surgery for an acoustic neuroma(AN). A sub-occipital approach was used. I am now 71 years old and my surgery was done in Vancouver in June of 1969, when I was 24 years old.

It has been over 30 years since I first heard of ANAC and I've been involved ever since. It is so nice to know you are not "alone" in this journey with an Acoustic Neuroma. It is truly not the end of the road, but a slight detour. I have met some wonderful people along the way too.

I have a slight balance problem, left sided deafness, tinnitus (a nuisance), and a left sided facial palsy. OH, and the ever dry left eye. Back in 1991, I had a "gold weight" inserted in my left top eye lid. This has been so helpful in protecting me from the elements of the air. Also I use eye drops daily - first thing in the morning, and at bedtime, and whenever I need them during the day. Occasionally when I get a flair-up, an infection, or an ulcerated cornea, I use the lubricant until it clears up. Sunglasses are a must too!

My 45-year-old daughter is now presenting with symptoms of an Acoustic Neuroma. I would like to know if you have a family member with the same.

As said earlier, this is just a detour. I think as we age, we learn to appreciate many small things daily, in life. For me, first of all, my faith in God is very important, then my family - my husband of 50 years of marriage, our grown children and grandkids, friends, health, and the birds we hear and flowers, etc.

I am the B.C. Chapter Leader for ANAC and am always willing to receive emails and phone calls if I can be of help to anyone. We meet in in Courtenay on Vancouver Island for an AN gathering.

Our next meeting is **Saturday October 1, 2016.**

Evalyn Hrybko,

250-282-3269/ wehrybko@saywardvalley.net

"Life is a gift, and it offers us the privilege, opportunity, and responsibility to give something back by becoming more."
Anthony Robbins

Evalyn, who amplifies this quote, is a former school teacher and today her and her husband act as foster parents - very often with a couple of children with many challenges. Often remarked *"True Kindness Is Doing Something for Someone Who Can't Repay You"*

Upcoming Chapter Meetings Planned

KITCHENER—WATERLOO CHAPTER

Date: **October 2016 (date to be determined) 10am—12 noon followed by a potluck lunch**
Location: Home of Tom & Helene 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 COLUMBA: COURTENAY/NANAIMO CHAPTER

Date: **Saturday, October 1, 2016**
For more info: Evalyn Hrybko
(250) 282-3269 / hrybo@saywardvalley.net

TORONTO CHAPTER

The upcoming meetings are:
Dates: **Tuesday, September 27, 2016**
Tuesday, November 29, 2016
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 / tim.harrod@sympatico.ca

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