The Connection

Spring Edition 2020

A Publication of the Acoustic Neuroma Association of Canada

Association pour les Neurinomes Acoustiques du Canada

www.anac.ca

Inside this issue:

Patient Decision-Making in Vestibular Schwannomas

By: Dr. Hamid Djalilian

A collaborative study between the University of California, Irvine Neurotology and Skull Base Surgery Division and the Acoustic Neuroma Association was recently published in the journal Otology and Neurotology. The survey was completed by 789 members of the ANA, allowing surgeons to better understand the critical decision-making process patients use in choosing surgery, radiation, or observation.

It was determined that of the 789 participants, 629 (80%) saw multiple AN specialists and 410 (52%) sought second opinions within the same specialty.

Of those who received multiple consults, 242 (59%) of patients reported receiving different opinions regarding treatment. Those who elected to choose observation instead of intervention spent significantly less time with the physician (41 minutes) compared to surgery (68 minutes) and radiation (60 minutes) patients.

A total of 32 (4%) patients stated the physician alone made the decision for treatment, and 29 (4%) felt they did not understand all possible treatment options before a final decision was made. Of the 414 patients who underwent surgery, 66 (16%) felt they were pressured by the surgeon to choose a surgical treatment. It is common for AN patients to seek second opinions from physicians of different specialties and within the same speciality. Our findings

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demonstrate that those who seek second opinions have higher satisfaction rates as well. Thus, physicians should facilitate and help patients seek second opinions to better understand the various treatment modalities that can be offered.

80	Percentage of patients in sample who saw multiple AN specialists for an opinion.
Percentage of patients in sample who sought second opinions within same specialty.	52
59	Percentage of patients who received different opinions from doctors about treatment

Hamid Djalilian, M.D is Director of Otology, Neurotology, and Skull Base Surgery Department of Otolaryngology – Head and Neck Surgery University of California, Irvine. Prior to UC Irvine, he was on the faculty at the University of Illinois, Cedars Sinai Medical Center, and UCLA. Dr. Djalilian's areas of expertise include complex ear surgery, hearing loss, balance disorders, facial nerve paralysis, and skull base surgery.

American author, Leo F. Buscaglia, offered this succinct advice:

"When you doubt your power, you give power to your doubt"

I've never thought of power in that way. From now on I will trust my power, giving power to my trust. Then I will proceed with what is in front of me in the moment and do my very best.

A Message from the President

The ANAC Board of Directors hopes that you and your loved ones are keeping safe and healthy. Never has this message been more difficult to compose as we hunker down in our homes to help curb the spread of COVID-19. And never have the words of the ancient Greek philosopher, Heraclitus, echoed more distinctly: the only constant in life is *change*.

In this state of flux, what we choose to say at the moment of writing may sound quite preposterous by the time our newsletter reaches our members . . . or perhaps even in just a few hours from now! One thing, however, is certain: as long as we maintain good health during this crisis, ANAC will be here for our members. We are particularly concerned about those of you who are battling your own private nightmares dealing with an Acoustic Neuroma diagnosis -- and the agonizing treatment decisions that go with it -- on top of facing the fears and uncertainties surrounding the corona virus. I was in touch with one member recently who told me that her much-anticipated spring surgery has been put on hold. She's at peace with that, however, not really wanting to be in a hospital at this time and considering the intense strain that's currently being put on our doctors and medical personnel.

Unfortunately, our much-anticipated ***World of Acoustic Neuroma 2020 Symposium***, originally scheduled for June 27th, is also being postponed. Even to contemplate a future date at this point may be somewhat futile; nevertheless, in an attempt to remain positive, we have ***pencilled in Saturday September 26th*** as a possibility. Obviously, no one knows what will be happening in the meantime, and we will simply have to be in touch with everyone again in the fullness of time.

On a very sad note, we recently learned of the passing of one of ANAC's three founding members, Linda Gray, on March 21st. Linda was just 71 and had suffered from Alzheimer's disease. Virginia Garossino, the remaining founding member and a good friend of Linda's, has written a tribute to her in this issue. Those of you who attended our AGM last fall will have heard a message that Virginia had requested to remember her at the meeting.

Virginia remarked that "one the highlights of my life, as strange as it sounded, was having an acoustic neuroma as it taught me to overcome unimaginable challenges and to share the knowledge and how to overcome obstacles.....We were on our way to what I used to call the *Johnny Appleseed approach*: *spread enough apple seeds and you will eventually have an orchard*.

Finally, remember that you can continue to contact our Executive Director, Carole Humphries, as well as our Chapter leaders with your questions and/or concerns. Please refer to the back page of this newsletter for their email addresses and telephone numbers. Also, we urge any of you who

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may know other ANAC members to be in touch with them to see how they are doing. Sticking together (remotely!) and trying to maintain a sense of humour will be the best tonic to help us get through this exceedingly trying time. Wishing everyone good health!

E. Judy Haust

Routings are Important: Routines are Comforting

After talking with a long-time friend about the importance of routines during this unprecedented time, Dana forwarded this note which I wished to share with you.

This is Dana's tongue-in-cheek message:

1. Develop a To Do List.
2. Divide the To Do List into three categories:
   Things that must be done
   Things that it would be nice to do
   Things that it would be enjoyable to do.

3. Prioritize the many items under each of the three headings.
4. Decide to put off until tomorrow all of the items under Headings 1 and 2.
5. Do the first thing in the list under Heading 3 — if you have the time and the inclination.
6. If you don't have the time or inclination to do any of the enjoyable items under Heading 3, congratulate yourself on your self-sacrifice and make them the first items on the list for tomorrow.

I hope this helps. It has helped me!

Carole Humphries

Rituals are comforting; rituals combat loneliness.

John Irving

Hearing Aid Basics for Patients with an Acoustic Neuroma

By: Christine Kenney, M.H.Sc and Emily Dawber, M.Cl.Sc.

There are many things to keep in mind when looking into getting hearing devices. The duration and the severity of the hearing loss in the affected ear (the ear which has/had the acoustic neuroma), and in the non-affected ear, will influence your experience with amplification. The most important thing to keep in mind is that it always takes time to get used to amplified sound. It is quite common for certain environmental sounds (for example: water running in a sink, dishes clattering, papers rustling) and certain speech sounds (for example /S/ and /SH/) to sound louder and unnatural. You may find that amplified sound is too sharp or too tinny, that your own voice may sound loud or echo, and that familiar sounds in the environment may sound very different than before. It can take several weeks to several months of regularly using hearing aids for these sounds to become more normal.

This brings us to another important point; be patient with yourself and go at your own pace. Ideally, you would wear the hearing device most waking hours of the day, apart from when you are showering or going for a swim. However, every person is different - if you feel comfortable wearing the hearing device for 16 hours a day, that's great! If you prefer to take it more slowly, you can gradually work your way up to a full day of wear. Try to wear the devices for at least six hours a day. You can always wear them in quieter environments to get familiar with the sound quality before wearing them in a more challenging environment, like a restaurant.

Even the best hearing aids are never going to sound as good as normal hearing. For most people with age-related hearing loss, their ears are like radios with the volume turned down - a hearing aid is like turning up the volume, the sound will be loud and have good clarity. For most patients with acoustic neuromas, their ears are like a radio with the volume turned down *and the dial tuned slightly off-station*. Just like a radio, there is some 'fuzz' or distortion. When a hearing aid brings the volume up, it is definitely easier to hear, but the quality of the sound isn't perfect. Amplified sound coming from a hearing device cannot fix the damage in the ear and the nerve.

The ability to localize sounds (or determine where sounds are coming from), the ability to hear speech when there is background noise, and even the clarity of the sound can be impacted when there has been an acoustic neuroma or hearing loss from other causes. While hearing devices can make it easier to hear some sounds that were not heard before and easier to hear in more difficult environments, it is no replacement for a healthy auditory system. It is important to have realistic expectations when getting used to a new device.

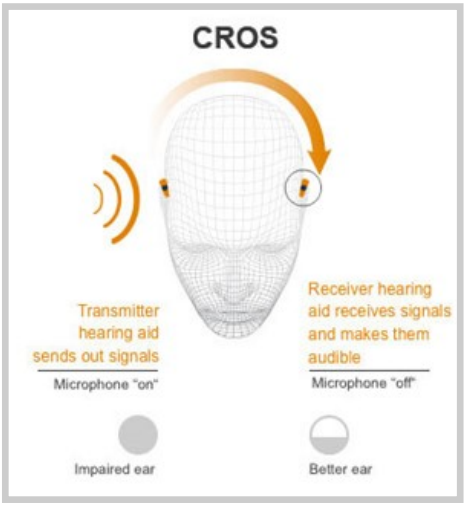
Now let us look at the different types of amplification available. Among the following types of amplification there are different manufacturers, models and costs. All of these factors should be discussed with your audiologist when it comes time to make your decision.

Hearing Aid Basics for Patients with an Acoustic Neuroma

1) **Hearing aids**: This is the type of amplification most people are familiar with. There are hearing aids that fit into your ear canal (invisible in the canal, completely in the canal, in the canal and in the ear styles) and others that sit behind your ear with a piece fitting in your ear canal (behind the ear or receiver in the canal styles). Depending on the degree of hearing loss and the clarity of speech in the affected ear (among other things) as well as the degree of hearing loss in the non-affected ear, either one or two hearing aids may be recommended.

2) **Masking devices**: Approximately 60%-70% of people with tinnitus (a perception of ringing, buzzing or other noises in the ear) will notice some improvement in their tinnitus when wearing a hearing aid. However, if a hearing aid alone is not enough to manage the tinnitus, a masking device can help. Some hearing aids have a masking feature which essentially will produce a soft sound (white noise, water noise, chimes etc.) to help distract your brain from the tinnitus. Not all hearing aids have this masking feature available. If your tinnitus is bothersome, this is something to discuss with your audiologist when choosing which type of device will be best suited for you.

3) **CROS and Bi-CROS**: these devices are used when the affected ear isn't a good candidate for a hearing aid. The amount of hearing loss or remaining clarity may be so poor that a hearing aid on that ear wouldn't help you understand speech. A microphone on the poorer ear picks up the sound, and sends it over to a hearing aid on your better ear. A CROS is used when the better ear has normal hearing. A biCROS is used when the better ear has some hearing loss, and needs some additional amplification. CROS and biCROS systems sometimes take a bit of time to learn to localize sounds, as the brain has to retrain itself hearing all of the sounds coming from the better ear.



Hearing Aid Basics for Patients with an Acoustic Neuroma

Most hearing aids have options for rechargeable batteries, streaming calls and music from your smart phone, and acting like a wireless headset for your television. These are all things to discuss with your hearing care professional.

Some people who are not successful with hearing aids or CROS/biCROS systems are candidates for other devices - such as a bone anchored hearing aid (BAHA) or a cochlear implant (CI).

This is not something that you will be doing alone. Make sure to find a hearing care professional that you feel comfortable working with. There are usually a few visits needed to get things sounding right. It is also important to educate your family, friends and co-workers. Even if you have done everything up to this point perfectly, you will still have difficulty understanding speech if the people around you do not communicate correctly. In all environments, but especially in challenging ones (for example restaurants, parties and family gatherings) make sure everyone is using the correct communication strategies. Ensure that the person talking to you gets your attention before they begin speaking, that they are looking at you and that you are looking at them. Someone with no formal training can still get some benefit from lip reading. Ask people to speak slowly, clearly and loudly (without shouting as that can make it harder to understand what is being said). If you need to have someone repeat themselves, you can ask them to rephrase rather than repeat. You are doing your part by wearing a hearing aid - they need to do their part by having good communication habits and understanding that hearing aids don't give you normal hearing. Lastly, be patient with your family, friends and co-workers, as they may need some time to learn better communication habits.

Christine Kennedy grew up on Vancouver Island, where she obtained her Bachelor of Science in Neuropsychology at Vancouver Island University. She moved to Ottawa to pursue her Master's in Health Science in Audiology at the University of Ottawa.

Emily Dawber graduated from Queen's University with a BAH in Psychology and completed her Master's of Clinical Science in Audiology at the University of Western Ontario.

Christine and Emily have both been with Costco since 2015, currently practising in the Ottawa area.

COSTCO WHOLESALE

Blindness separates people from things; deafness separates people from people.

Helen Keller

Bridging the Gap – My Road to Enhanced Hearing

By: Nick Kucharew, Fox River, Nova Scotia

My story begins in 2011 when I discovered I had an acoustic neuroma. I suddenly lost my hearing in the right ear. Next came an MRI, appointments at Sunnybrook Hospital, and the decision to *Wait and See . . .*

In September 2014, I had surgery to remove the tumour using the translabyrinthine approach. The result, successful removal!!! However, this meant that my balance nerve* was also removed, and I was left with single -sided deafness [a necessary result of translab surgery].

Jump forward to early 2015: after researching various options to help with my lost hearing on the right side, I came across the Bonebridge Bone Conduction by Med-EL. The Bonebridge, an active bone conduction implant, is inserted under the skin on the tumour side of your head, and an external SAMBA audio processor is magnetically coupled to the implant's coil.

How Does it Work?

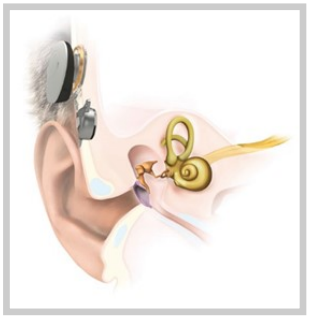
In a person with normal hearing, sound vibrations are sent through the outer and middle parts of the ear and on to the inner ear.

If you have single-sided deafness like me, the BONEBRIDGE can pick up the sound vibrations on your bad side and send them through to your inner ear on the good side. This results in much improved hearing on the damaged side.

The system consists of the SAMBA Audio Processor and a Bone Conduction Implant.

See link to a video that illustrates how it works: https://www.medel.com/hearing-solutions/bonebridge

NOTE: The audio describes conductive or mixed hearing loss, which is where your outer (or middle ear) is damaged, but your inner ear to hearing nerve is intact. As I had single-sided deafness and my inner ear to the hearing nerve was not intact, sending the signal to the damaged side's inner ear would not work. But it does work when sent to the inner ear of the "good side", which has an intact inner ear to hearing nerve connection.



What Does this Mean for the Wearer?

The Pros: I would like to note the BONEBRIDGE Bone Conduction Implant surgery I had in 2015 was a quick one, about one hour. It went very well with no ill side effects.

I remember driving home with my wife, and we decided to stop for lunch at my favourite breakfast place. It was EXTREMELY noisy and normally that would have hurt and been intolerable. I sat there and could not believe how well I was handling the noise all around me. That is a most welcome benefit of the implant with audio processor.

Bridging the Gap - My Road to Enhanced Hearing

The other thing I noticed after months of wearing it was that I was not as tired by midday. As many of you know, when you are deaf on one side, trying to hear people talking and make out what they are saying is very tiring. It was significantly better with this device.

Also, the device attaches easily as it has a simple magnetic coupling, and the implant is completely under the skin, so no infections, irritation, and so forth. Batteries are about 25 cents a piece, last a week, and are easy to replace.

Finally, the audio processor can be upgraded. This is a particularly nice benefit as new features, better processing, etc., become available. Although the device is not perfect, it is comfortable, works well in picking up sounds and pretty good overall.

The Cons: The biggest downside I find is that while the Bonebridge picks up sound on my deaf side, the volume I get is perhaps 20% or so. I wish it were closer to the volume I hear at on the good side.

Sometimes it has fallen off, even with the safety clip, and at a cost of approximately $5500, you do not want that happening too much!!

NOTE: Determine what support is available for hearing devices in your province from an audiologist / hearing devices specialist.

The audio processor is capable of using wireless and Bluetooth, but through another external device, the Siemens MiniTek. I found it worked well with some things such as a personal mic headset my wife wears and listening to the TV with a transmitter attached. But, all in all, it is more trouble than it is worth to continually setup the equipment to make it work. Needless to say, I don't use it that way much anymore.

Wearing the device with hats is somewhat problematic as you must play with fit of your hat, and usually there is still some feedback, which can be a bit bothersome. You also need to be careful to not wear it into the shower, swimming, etc. I have got it wet on occasion and, fortunately, it held up quite well.

In summary, the Bonebridge has allowed me to handle day to day life much better. I am less tired, have better speech discrimination, and I'm much better able to handle noisy environments.

Nick Kucharew, who is a member of the ANAC Board of Directors, has been instrumental in kickstarting and developing the dynamic ANAC website. He and his wife recently moved from Burlington, Ontario, to Fox River, Nova Scotia, where they are enjoying nature, the slower pace of life, friendly people, and usually can be spotted hiking the nearby country trails. *Nick's previous article, "A Little Off-Balance but Not Out of Step" can be found under Our Stories on anac.ca.

kucharen@gmail.com

Acoustic Neuroma Research Abstract

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

Neurosurgery. 2018 Feb 1;82(2): E32-E34. doi: 10.1093/neuros/nyx510.

Congress of Neurological Surgeons Systematic Review and Evidence-Based Guidelines on the Role of Imaging in the Diagnosis and Management of Patients with Vestibular Schwannomas.

Dunn IF[1], Bi WL[1], Mukundan S[2], Delman BN[3], Parish J[4], Atkins T[5], Asher AL[5], Olson JJ[6].

QUESTION 1: Is there a role for advanced imaging for facial nerve detection preoperatively?

RECOMMENDATION: T2-weighted MRI may be used to augment visualization of the facial nerve course as part of preoperative evaluation.

QUESTION 2: What is the expected growth rate of vestibular schwannomas on MRI, and how often should they be imaged if a "watch and wait" philosophy is pursued?

RECOMMENDATION: MRIs should be obtained annually for 5 years, with interval lengthening thereafter with tumour stability.

QUESTION 3: Do cystic vestibular schwannomas behave differently than their solid counterparts?

RECOMMENDATION: Adults with cystic vestibular schwannomas should be counseled that their tumours may more often be associated with rapid growth, lower rates of complete resection, and facial nerve outcomes that may be inferior in the immediate postoperative period but similar to non-cystic schwannomas over time.

QUESTION 4: Should the extent of lateral internal auditory canal involvement be considered?

RECOMMENDATION: The degree of lateral internal auditory canal involvement by a tumour adversely affects facial nerve and hearing outcomes and should be emphasized when interpreting imaging for preoperative planning.

QUESTION 5: How long should vestibular schwannomas be imaged after surgery, including after gross-total, near-total, and subtotal resection?

RECOMMENDATION: For patients receiving gross total resection, a postoperative MRI may be considered to document the surgical impression and may occur as late as 1 year after surgery. For patients not receiving gross total resection, more frequent surveillance scans are suggested; annual MRI scans may be reasonable for 5 years. Imaging follow-up should be adjusted accordingly for continued surveillance if any change in nodular enhancement is demonstrated.

* * * * *

In Memoriam—Linda Gray

The Acoustic Neuroma Association of Canada (ANAC) was founded in 1983 by Virginia Garossino, Velma Campbell and Linda Gray, of Edmonton. Finding strength within each other and realizing there were few resources available to them, they established ANAC, a charity dedicated to support the complex needs of those affected by an Acoustic Neuroma. In October 2007, the national office was relocated to Ontario. Sadly, Linda Gray passed away on March 21st, just short of her 72nd birthday.

When Linda and I first met, we felt a connection, like kindred spirits . . . where had we known each other? We were not alike and, had we not each had an acoustic neuroma, we would probably never have met. But we did, and this is our story.

I "accidentally" met Linda Gray in the physiotherapy waiting room at University of Alberta. Linda had heard of Velma Campbell, so the three of us (along with two hubbies) got together to found ANAC. Velma and George provided the legal and accounting work, and publicity contracts. My husband, Dick, and I supplied a fully equipped office with computers and IT assistance from my business and communications company. Linda was to be the office manager. Over several meetings, we built the organization, complete with brochures, newsletters, medical databases, community resources, etc., all designed to answer peoples' questions about ANs. It was time to go public -- Linda and I did a radio interview and the phone lines went wild. We were ecstatic to have this response in Edmonton. We were on a roll!

Linda's background as a lab technician, together with a natural curiosity and need for detail, gave her an amazing capacity to organize and use data. She was empathetic, listened to people and kept copious notes. This formed the basis of a database, which was used to connect people and encourage the birth of chapters. Linda successfully spearheaded our application for federal funding with probably the most detailed application the government had ever received. Her encouragement and support for chapters was unparalleled. She developed a volunteer team to work with her, and the growth was exponential.

After 15 years of caring and helping people, Linda decided to follow the path of holistic health and healing, and left ANAC to follow her dream. She opened a home-based business, offering sessions in Touch for Health, Reiki, and Hand and Foot Reflexology. Dick and I were often her "patients" in her tests and demos, a bonus for us. I was always a willing body to practise on, and her touch was magic.

Together we built something special in ANAC, giving it our best, enjoying every minute of it. I can't imagine the world without Linda's her energy, and I'm beyond thankful that she was in my life. I am so much richer for it and will always treasure the memories and feel the healing touch.

Virginia Garossino, Vancouver

Upcoming Chapter Meetings Planned

KITCHENER—WATERLOO CHAPTER

Date: **TBD 2020**—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: **TBD 2020**—1pm
Location: White Spot, 2299 Cliffe Ave., Courtenay, BC
For more info: Evalyn Hrybko
(250) 282-3269 / wehrybko@saywardvalley.net

TORONTO CHAPTER

Dates: **TBD 2020**—Tuesday 6:30pm—8:30pm
Location: Canadian Hearing Society
271 Spadina Road, Toronto, ON (Parking in the rear)
For more info: Kathryn Harrod
(905) 891-1624 / kath.harrod@live.ca
Linda Steele
(416) 993-0065 / lindasteele2@gmail.com

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