The Connection

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Association pour les Neurinomes Acoustiques du Canada

www.anac.ca

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New Accessibility Tools

To serve individuals with “speech, physical, hearing and vision” related impediments, Bell announced on February 29, 2016 that it now has devices which have a component to meet their specific requirements.

All carriers in Canada are now mandated by Canadian Radio-television and Telecommunications Commission (CRTC) to offer at least one mobile headset to people who are “blind and/or have moderate to severe mobility or cognitive disabilities.”

Information about Bell’s portfolio of accessible products and services is available at the new online Accessibility Services Centre at Bell.ca/Accessibility. To meet the Web Content Accessibility Guidelines AA rating, Bell’s Accessibility Services Centre provides enhanced navigation for screen readers and keyboards. A Mobile Device Selector tool is also available to help customers find devices with features such as screen magnification, TTY compatibility and guided access mode.

In the coming months, Bell will also be introducing a dedicated wireless rate plan for the approximately 357,000 Canadians that are deaf or hard of hearing.

Details about ANAC’s 2016 Symposium on page 11.

INTERESTED IN JOINING THE ANAC BOARD OF DIRECTORS

This is an opportunity to pay it forward and help individuals diagnosed with an Acoustic Neuroma. We are looking to augment the talent on our Board. Candidates will have a broad range of skills and experience. Commitment includes: two year term; monthly board meetings (video conference); and committee work.

To learn more and submit your resume contact: Carole Humphries, Executive Director at info@anac.ca

How Ironic: A Vestibular Therapist gets a Vestibular Schwannoma

By: Robynne Smith, Saskatoon Saskatchewan

My career as a physiotherapist started with treating children for ten years ago in Regina, after which I started in private physical therapy clinics in Saskatoon. It was in the 1990s that I started having an interest in Vestibular Therapy and travelled many times to the US for training. I loved my career and I was able to help many people with dizziness and balance concerns. In 2010, I started have to have altered sensation on the left side of my tongue and when it became constant, I saw a doctor. Two weeks later an MRI showed that I had an acoustic neuroma measuring 2.2 x 2.4 x 2.6 cm. At the time I did not have any balance issues or any significant dizziness and my hearing was fine. I was very surprised at the size of the tumor given that my only symptom was my “fuzzy tongue”.

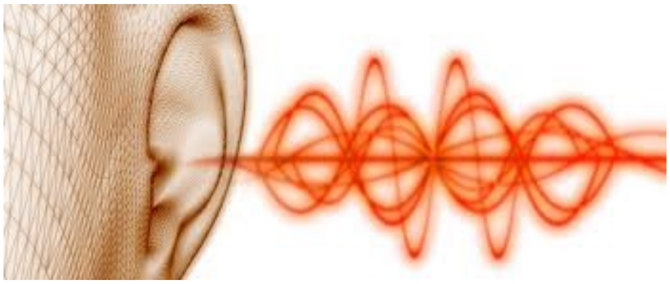
In 2011, I went to Winnipeg for gamma knife radiation. I believe the contraption that was screwed onto my head caused my skull bones to shift and created left temporal pain which lasted a long time. I continued working for the next few years but gradually noticed symptoms of left sided hearing loss which I started self-monitoring with iPhone apps. My balance was still fine and still no dizziness. I went off work in September 2013 because of severe migraines, which later turned into pressure/ fullness in the back of the head. In early 2014 I had a prism on my glasses for double vision. I was no longer driving, losing weight and not thinking clearly. I am so thankful for my neurologist who knew there was a problem and found the hydrocephalus despite the size of the tumor not changing significantly. I was sent directly to ER and surgery was one week later.

The six hour surgery was on March 31, 2014 with three specialists looking after me. Upon regaining consciousness, it became apparent that the left side of my face had lost sensation and muscle function despite the facial nerve being monitored by a medical physicist during the procedure. I used a walker for a few weeks, progressing to poles and on discharge from neuro rehab on May 1, 2014 I was walking unaided. I believe my balance was so good before and after surgery because of what I did with all my clients over all the years.

I wish my eye had fared as good as my balance did. While in the rehab hospital I had damage to my left cornea and my eye has been stitched closed since Easter weekend, 2014. I am thankful that I am able to drive and function almost normally, with the exception of depth perception and loss of left visual field, leading to a few less dishes in my kitchen!

This has been a long journey since September, 2013 but the recovery of my face continues as I am approaching the two year anniversary of my surgery. I am looking forward to having binocular vision once again after the first surgery on April 19, 2016 after which I will have a corneal transplant later in the year. I am also looking forward to being a contact person for ANAC in Saskatchewan.

Severity and Treatment of Tinnitus in Acoustic Neuroma



There is a high prevalence of tinnitus in individuals with acoustic neuromas which has been corroborated by many studies. In 2014, a study surveying 143 participants was conducted by University of California, San Francisco to address two questions:

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

It queried demographic features, tumor size and sidedness, hearing function in each ear, type of treatment: microsurgery, stereotactic radiosurgery, fractionated therapy, or observation, and elapsed time from treatment. A Tinnitus Functional Index, which is an instrument to assess tinnitus severity used the following scale from 1- 100 points as follows: **a)** "not a problem" (0-20); **b)** "small problem" (21-30); **c)** "moderate problem" (31-40); **d)** "big problem" (41-60); **e)** "very big problem" (61-100).

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

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

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

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

On the Horizon

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

Severity and Treatment of Tinnitus in Acoustic Neuroma

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

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

Tinnitus Research Update

Researchers at Georgetown University Medical Center (GUMC) in Washington, D.C., and the Technische Universität München (TUM), Germany, have announced that they have uncovered the brain malady responsible for tinnitus and chronic pain. “Identifying the problem,” they observe, “is the first step to developing effective therapies for these disorders, which afflict millions of people.”

The lead researchers are Josef Rauschecker, PhD,DSc, director of the Laboratory for Integrative Neuroscience & Cognition at GUMC, and Markus Ploner, MD, PhD, Professor of Human Pain Research at TUM.


Dr. Rauschecker

According to the September 2015 news release by GUMC: “The scientists describe how the neural mechanisms that normally ‘gate’ or control noise and pain signals can become dysfunctional, leading to a chronic perception of these sensations. They traced the flow of these signals through the brain and showed where ‘circuit breakers’ should be working – but aren’t...Tinnitus can occur after the ears are damaged by loud noise, but even after the brain reorganizes itself, it continues to ‘hear’ a constant hum or drum...Areas of the brain, in the limbic system, responsible for these errant sensations act as a central gatekeeping system for perceptual sensations, whether produced externally or internally...Tinnitus and chronic pain occur when the system is compromised.”

Possible therapy? “Because these systems rely on transmission of dopamine and serotonin between neurons, drugs that modulate dopamine may help to restore sensory gating,” states Dr. Rauschecker.

See “ Neuroscientists Uncover Brain Abnormalities Responsible for Tinnitus and Chronic Pain,” www.gumc.georgetown.edu/news, 10/17/2015

Tip: from Members

Thanks to LS from Toronto

Being diagnosed with an Acoustic Neuroma is very stressful. Having a support system such as friends and family is very important, but the best support system you can find is ANAC and its local chapters of the Acoustic Neuroma Organization. There you will find individuals who will help you on your AN journey with respect to treatment options, doctors etc.

Following surgery, the absolute best thing you can do is get rest and I can't stress enough how important this is. Support from friends and family to help with your day-to-day activities is just the beginning. Your body and brain need time to heal from the surgery and you will also need time to adjust to a "new normal" which may include single sided deafness and vestibular issues. It's best to make a recovery before returning to work and even then doing so at part-time hours to start.

Thanks to AA from Alberta

Microsurgery is a major medical undertaking. Why would anyone choose microsurgery if there is a viable option? The answer lies in long term vs. short term outcomes, and many feel microsurgery offers a more definitive way with lower risk of long term recurrence or other possible complications from radiosurgery. Others feel just as strongly that the opposite is true. There is no one perfect treatment that fits all situations.

Whatever approach you choose to handle your acoustic neuroma, remain positive. You are not going to make a wrong or bad decision on this. You are making the best decision for your medical situation in consultation with your doctors.

Please send your tip to Carole Humphries at info@anac.ca so we can share in the next edition.

"The best thing about the future is that it comes one day at a time." **Abraham Lincoln**

I really like the wisdom imparted in these words. If we concentrate on the fact that the future comes in such small increments we might be more inclined to live in the present. Imagine what you could accomplish if you lived each day that way.

The Waiting Game:
Why I let my brain tumor go untouched for 10 years

By: Carol Krucoff

Watching my little brain tumor grow slowly over the past 10 years has been an extraordinary exercise in courage, patience, gratitude and faith.

I learned about my tumor by accident in 2003 around my 50th birthday, when I'd had an MRI scan after collapsing from drinking too much water during a marathon.

Fortunately, my tumor is a benign and generally slow-growing type called an acoustic neuroma. Located inside my skull on the nerve responsible for hearing and balance, it measured just three millimeters - about the size of a sesame seed - when discovered. Although I had no symptoms, an expert I consulted recommended two possible treatments: surgery to remove it or radiation to stop its growth. While this tumor wouldn't metastasize, its growth could impair my facial nerves, balance and hearing, or even threaten crucial brain function. She advised acting early, when the tumor was small. Instead, I decided on a course of action known as "watch and wait."

Over a decade of watchful waiting, I've had 10 MRIs. Each of these scans was followed by a hearing test and a meeting with my doctor. I'm grateful to have health insurance, which means--in the most recent case--I paid $160 coinsurance for the $3,579 MRI, and $50 for the $960 hearing test/doctor's appointment.

The emotional cost, however, is harder to calculate.

When first diagnosed, I immediately went on the Internet and learned that most acoustic neuromas are slow-growing--but others increase rapidly. Anytime I felt dizzy or had trouble hearing, I worried. I joined a support group and met a woman whose surgery to remove an asymptomatic two-millimeter tumor had left her with crippling headaches and facial pain. I logged on to the discussion forum on the Acoustic Neuroma Association's website and read horror stories of botched treatments as well as wonderful examples of excellent results. After several months of almost daily trips to the forum, I became overwhelmed by the anxiety these posts aroused and signed off.

I tried to remain calm over the years as I watched my tumor's creeping growth, at a rate of about one millimeter - the size of a grain of sugar - a year.

Navigating an emotional tightrope between responsible vigilance and anxious obsession, I gratefully clung to the fact that I had no symptoms. My hearing and balance seemed unaffected. My yoga practice proved extremely helpful, since a central teaching is finding equilibrium - that steady place between effort and surrender - which is the key to watchful waiting. I found comfort

The Waiting Game

in viewing the experience as an opportunity to cultivate gratitude and faith, and I meditated daily on visualizing the dissolving of my tumor.

By 2006, about three years after it was discovered, my tumor had grown to six millimeters - about the size of a pea. At my doctor's urging, I met with a radiation oncologist, who recommended that I undergo radiation treatment intended to halt the growth.

But since I was still asymptomatic and the tumor was still small, I chose to continue watchful waiting. I'd read that some tumors stop growing on their own, and I hoped this would be the case with mine.

In April 2013, based on an article I had written about the accidental discovery of my tumor, I was asked to testify before the Presidential Commission for the Study of Bioethical Issues at a meeting devoted to the ethical implications of incidental findings. Representing the patient's perspective, I told the panel, "As a health journalist I'd always thought there was great benefit in early detection. However my experience has made me question the wisdom of learning about an abnormality if all it offers is anxiety – as well as potential harm from treatments for something that might never affect my health."

Yet when a panel member asked me, "Do you really wish that you simply had never been told?" I had to admit, "Definitely no. If [the doctors] know, I want to know. I wouldn't want to be shielded for my own protection. That's my decision; this is my brain." I urged the panel to keep patients informed "in simple, direct language of what's been found and its implications for health" and to "consider adding a support person to the health-care team, such as a social worker or psychologist, to help the patient and their family process the information and decide on a course of action."

Ironically, four months after my testimony, I had my scheduled MRI and hearing tests and learned that my tumor now measured 1.2 centimeters - about the size of a small walnut.

While I still had no symptoms, tests of my vestibular function - the sensory system that contributes to balance - on the affected side were abnormal even though I had not experienced

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balance problems. Continued growth would now mean a strong likelihood of negative effects on my hearing and facial nerves. A common way people learn of an acoustic neuroma is sudden, one-sided hearing loss, which may be permanent. So perhaps my incidental finding had been a blessing after all. It was time to take action.

I spent six weeks visiting brain surgeons and radiation oncologists, spoke with patients who had chosen each approach, then made a decision to have what is known as gamma knife radiosurgery.

In my decade of waiting, there had been significant advances in this minimally invasive treatment option, which uses imaging to direct gamma radiation very precisely to a target point. The radiation is designed to inactivate further growth of the tumor. In the large majority of cases it is successful, but sometimes the tumor continues to grow and further treatment is necessary. And there are scary reports of rare instances where benign tumors turned malignant through radiation. Yet weighted against the potential risks of brain surgery – including likely hearing loss in one ear - the gamma knife seemed right for me.

In February 2014, I had the morning-long outpatient procedure, which involved being given a mild sedative and having a head frame attached to my skull, then lying very still, similar to what you do while having an MRI. I left the hospital in the afternoon with gauze wrapped around my head, feeling just a little unsteady, and rested the next few days. By the following week I felt fine, and I was back to teaching yoga.

MRI and hearing tests done six months and then one year later showed that my hearing and the tumor were stable. Thankfully, I have felt no ill effects from the procedure, although I have been told that effects of radiation may emerge years later. It could take at least two years after the radiosurgery to learn whether my tumor has stopped growing. After that, further scans are recommended at two, four and eight years. So I will be watching and waiting for some time. And I am not alone.

The boom in life expectancy – from about 47 years in 1900 to about 78 in 2012 – has resulted in an unprecedented "silver tsunami" of older adults, and technological advances mean an increased likelihood of finding some abnormality during those extra decades of life. While humans have

"What lies behind us and what lies before us are tiny matters compared to what lies within us." quotes Ralph Waldo Emerson, an American lecturer, and poet

Emerson who championed individualism encouraged people through the ages to look within and to pay attention to the talent and determination that are unique to each one of us. We can learn from his timeless words as we set our goals and take steps to carry them out.

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always been aware of our mortality, we have never been able to so clearly see the approaching train that may take us out.

For me, this unsettling knowledge presents a spiritual opportunity. Like the ancient yogis who were taught to imagine death sitting on their shoulder, having a heightened awareness of impermanence can serve to make the present moment that much sweeter.

And in my case, watchful waiting involves more than my little brain tumor. As with the old joke "What do you always look for but hope never to find?" (Answer: a run in your stocking), I'm continually monitoring a variety of conditions. I have regular echocardiograms to check my prosthetic bovine aortic heart valve. (I acquired this valve during open-heart surgery in 2008 to replace a congenitally abnormal valve that had become dangerously narrow and created an aneurysm that needed repair.) I have twice-yearly examinations by a retina specialist for a potentially precancerous "eye freckle" called a choroidal nevus. A dermatologist checks multiple moles on my skin once or twice a year, and every five to 10 years I have a colonoscopy to check for polyps, since there's a family history of colon cancer.

That said, I'm grateful to feel quite well, thank you. I walk my dog several miles every morning, practice yoga daily and teach yoga classes. My friends marvel at how such a healthy person can have such a long list of medical problems, and they often compliment me on my bravery. The truth is, I've been terrified facing brain radiation, open-heart surgery and other challenges, and I have had some dark moments. But I'm grateful to have wonderful family and friends to support me, and I don't want to weigh them or myself down with prolonged upset. Life is too short to waste precious time wallowing in worry. And I've learned that courage isn't the absence of fear - it's being afraid but doing what you need to do anyway.

Krucoff, a former Washington Post writer and editor, is a yoga teacher at Duke Integrative Medicine in Durham, N.C. She has written for publications including The New York Times, Reader's Digest and The Huffington Post and is author of "Yoga Sparks: 108 Easy Practices for Stress Relief in a Minute or Less." Carol's passion for "movement as medicine" is rooted in a deep personal commitment to the healing power of physical activity. Her website is at healingmoves.com.

This article first appeared in February 2016 in the Washington Post.

INVITATION TO MEMBERS

Inspire others and share your experience

In your story include how you were diagnosed, pre-during-post stages of your treatment/ experience as well the support that have helped you and lessons you have learned.

To submit your story, contact: Carole Humphries, Executive Director

Support Groups Across Canada

People who are diagnosed with an Acoustic Neuroma and their loved ones, often find help through an Acoustic Neuroma support group. Through support groups, people who have experienced Acoustic Neuroma, gather to share information, experiences and offer to support to one another. Within the safety of a support group, many people are able to share their past experiences, their fears and concerns about the future, and the day-to-day challenges they face. Support groups may also present speakers from the medical professional community to educate about Acoustic Neuromas.

Acoustic Neuroma support groups are located in various locations in Canada in the cities shown below.

For more information on meeting times and locations, please contact the individuals from the listing. Please contact the National Office at **1-800-561-2622** or **info@anac.ca** to speak with other patients in your region.

Alberta: Edmonton
For further information contact:
Contact: Mary Jane Hradowy at 587-216-4448 or
Email: maaavelouse@me.com

British Columbia: Courtenay / Nanaimo
For further information contact:
Evalyn Hrybko at 250-282-3269 or
Email: wehrybko@saywardvalley.net

Manitoba: Winnipeg
For further information contact:
Faye Gorenson at 204-762-5611 or
Email: fsg@mts.net
Annamaria Palffy at 204-254-4409 or
Email: palffya@hotmail.com

National Chapter, Ottawa
For further information contact:
Contact: Nick Dinelle at 613-831-2426 or
Email: ndinelle@rogers.com or
Facebook: ANAC OTTAWA/OUTAOUAIS

Ontario: Kitchener / Waterloo
For further information contact:
Linda Darkes at 519-696-3445 or
Email: pdarkesc659@rogers.com
Helen Horlings at 519-954-5581 or
Email: healto@rogers.com

Ontario: Toronto
For further information contact:
Lynda Nash at 416-282-0036 or
Email: lynda_lu123@sympatico.ca or
Kathryn Harrod at 905-891-1624 or
Email: tim.harrod@sympatico.ca

Ontario: London
For further information contact:
Margaret Dodgson at 519-451-3443 or
Email: dodgsonm@rogers.com or
Lorraine Swanson at 519-668-7737 or
Email: lor.anac@yahoo.ca

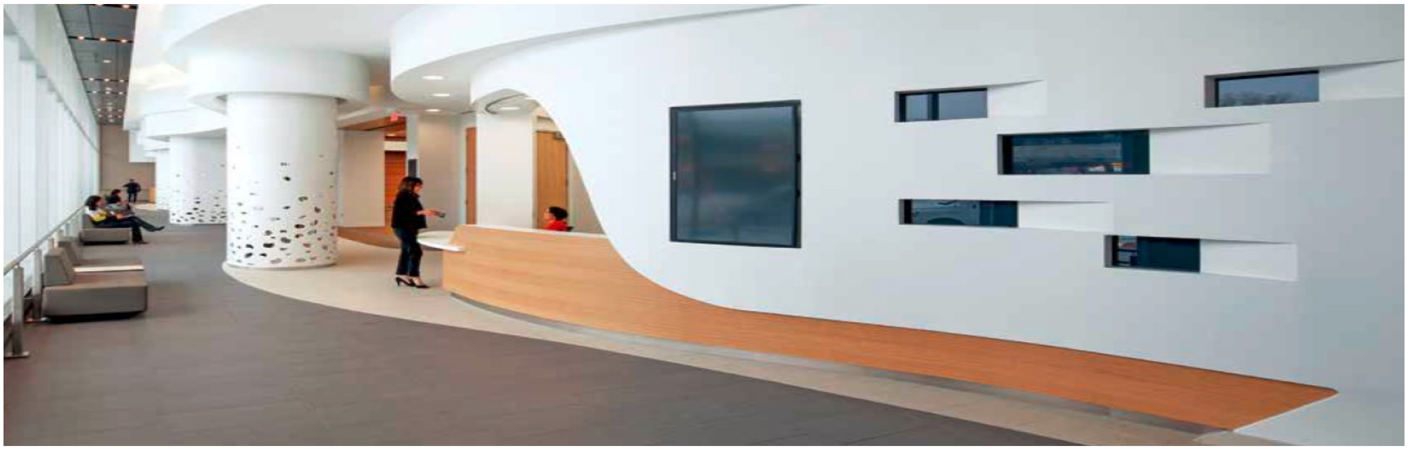
The Acoustic Neuroma Association of Canada is working to develop support groups in each province across Canada to ensure people affected by Acoustic Neuroma receive the support they need. Volunteers are currently needed in British Columbia, Quebec and all East Coast Provinces. If you are interested in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

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

The World of Acoustic Neuroma (Vestibular Schwannoma) ANAC Symposium: Saturday June 4th, 2016

Ever since ANAC's 2014 Symposium surpassed the expectations of the organizing committee, and received overwhelmingly warm praise from both speakers and guests, the board of directors has been busy planning the 2016 event! This year's event will be held at The Toronto Western Hospital's newly built BMO Education & Conference Center which is a state of the art facility.

In addition to featuring talks by physicians, surgeons and researchers from ANAC's medical board, we have also secured speakers that can speak on the management of AN rehabilitation. Communication Access Real-Time Translation (CART) will be used to close-caption the entire event for audience members with hearing difficulties.



Attendees will be able to not only to learn from leaders in their field but also to interact with the speakers and ANAC's medical advisory board through question and answer periods. This year, we will have a live webcast for our ANAC members across Canada who cannot make it to the event center.

Hope we see you there at the Symposium…

"Ask and it will be given to you; search, and you will find;
knock and the door will be opened for you."

Do you ask for what you want?
Do you search?
Do you knock?
Or do you go it alone as so many do?
You can reverse your course today by asking, searching, and knocking.

Upcoming Chapter Meetings Planned

KITCHENER—WATERLOO CHAPTER

Date: **Saturday, April 16, 2016 at 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: **May 2016**
For more info: Evalyn Hrybko
(250) 282-3269 / hrybo@saywardvalley.net

TORONTO CHAPTER

The upcoming meetings are:

Dates: **Tuesday, May 31, 2016**
Tuesday, July 26, 2016
Tuesday, September 27, 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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The Connection is prepared and edited by Jennifer Wong, ANAC Board Director.
Please forward all comments, feedback and story ideas to info@anac.ca