

The

# Connection



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Canada

Association  
pour les  
Neurinomes  
Acoustiques du  
Canada

[www.anac.ca](http://www.anac.ca)

## Spring Edition 2015

### Welcome to Spring!

After a long and arduous winter, no doubt all of you are looking to absorb the sun's rays, put away the tv remote and book covers and lap up some outdoor activity!

And what better way to enjoy some activity and help ANAC at the same time? For the first time ever, ANAC will begin an annual fundraising event, called ANAC Fun Days. And we are **Lyna Newman** inviting all our members to help raise funds so ANAC can get even better and help deliver much needed information and resources to everyone who is affected by the diagnosis of an Acoustic Neuroma brain tumour. Rather than ask everyone to participate in the usual fundraising events, we are inviting you to think of doing something you like best - whether it is a selling your world-renowned brownies, hosting a book club or participating in a bike ride or marathon. Do it on your own time, in your own space, with your friends and families. ANAC has chosen to kick off this event the week of **May 10th to 16th 2015** which is also Brain Tumour Awareness week. There is more to be said about this in this edition of our newsletter.



Thanks to Rex Banks, Chief Audiologist, Canadian Hearing Society for his insights into the wildly popular topic of dealing with Tinnitus.

Stay tuned for our next edition which will highlight some significant medical features. ANAC is lucky to have enlisted a notorious Who's Who of medical professionals to sit on our Medical Advisory Board.

All the best,  
*Lyna Newman*

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The Acoustic Neuroma Association of Canada provides information on a wide range of health and medical topics. While due diligence in collecting and reporting the information was followed, the Acoustic Neuroma Association of Canada does not warrant the accuracy of such information. The information contained herein is not intended to substitute for the advice of a physician, and you are advised always to consult your doctor for specific information and personal health matters. Unless otherwise specifically indicated, the naming of an organization, product, treatment, or therapy in this publication does not imply endorsement by the Acoustic Neuroma Association of Canada.

Your comments, ideas, suggestions, and financial support are needed and welcomed, and may be direct to:

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**Facebook:**

**Acoustic Neuroma  
 Association of Canada  
 –ANAC**

**Twitter: @CanadaAN**

## Reconnecting Via ANAC Chapter Meeting After 49 years!

The British Columbia Chapter met on Saturday October 25th in Courtenay, once again this was a successful AN gathering. There were eleven people in attendance; nine being AN patients. I had brought a 3½ year old boy, who was born deaf, to the meeting. I brought him along because he has had a cochlear implant, for the past year and a half. I wanted demonstrate how well he does with it. One lady at the meeting also has a cochlear implant (she is NF2 and deaf), they communicated not only with each other, but with all of us. Technology is amazing!

Another highlight of our meeting took place when two ladies were chatting, both mentioned "You sure look familiar". They had later discovered that they had been close friends as children. One family moved away when the children were about nine or ten years of age. They had been looking and thinking of for each other for 49 years. Who would have thought that AN tumours would have brought friends together after all these years!

There is a silver lining in everything, but sometimes we need to look for it !!!

All the best,  
*Evalyn Hrybko*

## Toronto Chapter 2015 Meeting Schedule

The Toronto Chapter meets every other month from 6:30 PM - 8:30 PM at the Canadian Hearing Society located at 271 Spadina Road, Toronto, ON.

Tuesday May 26, 2015 (*2nd Floor Aural Rehab Classroom*)

Tuesday July 28, 2015 (*3rd Floor Boardroom*)

Tuesday September 29, 2015 (*3rd Floor Boardroom*)

Tuesday November 24, 2015 (*3rd Floor Boardroom*)

For more information on joining the Toronto Chapter, please visit [www.anac.ca](http://www.anac.ca) or contact Chapter Leaders:

Lynda Nash at (416) 282-0036 or by email at [lynda\\_lu123@sympatico.ca](mailto:lynda_lu123@sympatico.ca)

Kathryn Harrod at (905) 891-1624 or by email at [tim.harrod@sympatico.ca](mailto:tim.harrod@sympatico.ca)

# Take The ANAC Days Fundraising Challenge

*Join us for the First Annual ANAC Days Fundraising Challenge*

*Kick Off Week May 10 to 16, 2015*

It's easy to participate, by organizing or hosting a third party event, you can raise funds for a cause that supports those diagnosed with Acoustic Neuroma (rare benign brain tumour).

## **There are many ways to organize or host your event:**

- Turn your junk into a donation; organize a yard sale or online auction
- Golf Lover? Organize a golf tournament
- Running enthusiast? A small walk or run-a-thon may be your event
- Use your culinary talents, organize a bake sale or pie auction
- Love to dance? Hold a community dance
- Love to eat? Approach your favorite restaurant about in-house fundraising ventures such as celebrity serving
- Green thumb? Organize a plant sale
- Fishing season is quickly approaching, how about a fish derby?

## **Large events to daunting?**

- Host a fundraising dinner party
- Challenge your friends to game of golf
- Celebrating a birthday or anniversary? Ask your friends to make a meaningful donation in lieu of gifts
- Organize a dress down or blue jean day at your office
- Challenge your family and friends to a friendly bowl-a-thon

However you choose to participate is up to you, each event will make a difference. This is a fun and rewarding way to support those who find themselves faced with a diagnosis of a rare benign brain tumour.

Share your ideas on ANAC's Facebook and Twitter pages, challenge your friends, encourage others to join in the fun!

To register your event and to receive your event package, please contact the National Office at [info@anac.ca](mailto:info@anac.ca) or by telephone at (800) 561-2622.

Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.

*~Margaret Mead*



## A Personal Experience - Tinnitus

*By: Evalyn Hrybko*

The chapters meetings help so many people. One goes to the Doctor for about 10-15 minutes, but then it is the rest of our lives we live and need to adjust constantly to the symptoms of the AN tumour, or loss of the AN tumour. For example, I am 45 yrs. post AN-op and recently had a nasty flair up of my tinnitus in both ears, which scared me. My husband reminded me that it usually happens when the weather is about to change and low and behold, the next day we instantly changed from a lovely and long summer to major rains and winds!

My tinnitus started about 8-10 months before surgery. At that time I had moments, and days, when I felt I just couldn't deal with it anymore. Yet somehow I'd get through each day. I still have tinnitus, but 90% of the time- if not more, I don't think about it. I have noticed that it gets worse in the winter months, especially with changes in the temperature. It is especially noticeable when going up and down the ski hill. When I shared this at a chapter meeting, a woman said to me after that it was a big help to her, in that the same thing happened to her and she thought she had another tumour forming. The Doctors are helpful, but if they have not had ANs themselves, they do not understand what we feel in our heads.

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## Response from an Audiologist

### *What's All The Noise in My Head?*

*By: Rex Banks, Chief Audiologist Canadian Hearing Society*



Rex Banks, M.A. CCC-A Reg. CASLPO  
Chief Audiologist  
Canadian Hearing Society

Most people would be surprised to learn that there is an internal alarm system located within their brain that is constantly monitoring the world around them. Basically, our central nervous system is idling in a state of readiness to respond to any type of “red alert” it may encounter. This idling causes “brain noise” that runs in the background. The majority of us are completely unaware of this brain noise until something triggers it to cross a threshold to become audible to some in the form of what’s called tinnitus.

Tinnitus is an auditory perception of a sound in the in the ear that can only be heard by the person experiencing it. Each person who has tinnitus describes it in their own way. Many report that it sounds like a ringing, buzzing, humming, clicking, whistling or roaring. It can be loud or soft, constant or intermittent, can change in pitch, and be heard in one or both ears. About 15% of the population experiences tinnitus with 5% reporting severely

intrusive tinnitus that affects their day-to-day activities.

## ***What's All The Noise in My Head? Continued***

It's important to understand that tinnitus itself is not a disease, but a symptom. It's your body's internal alarm system going off and telling you that something is not quite right. Tinnitus can be caused by a number of health conditions including high blood pressure, head trauma, dental problems, certain type of tumors, hearing loss and much more.

Your ears are always working but relax when they find a soothing background sound to listen to. They are geared to naturally want to listen to sound and are always scanning the environment for it. For people with hearing loss, the amount of environmental sound they are exposed to is reduced. This causes their ears to strain to hear what's around them and all of this straining increases their sensitivity to their internal brain noise which manifests as tinnitus.

So if you do have tinnitus, you should avoid silence as it only intensifies your sensitivity to your internal brain noise. For this reason, hearing aids are often recommended as a front line defense against tinnitus because hearing aids expose people with hearing loss to sound. For those who experience tinnitus but don't have hearing loss, custom ear sound generators may be recommended. In a nutshell, external sound decreases your sensitivity to internal sound.

Tinnitus can also be managed with the implementation of Tinnitus Retraining Therapy (TRT). Developed in 1990 by neurologist, Dr. Pawel Jastreboff, and audiologist Jonathan Hazell, TRT is the gold standard for tinnitus treatment. For those individuals whose tinnitus has become a significant annoyance, a systematic approach to 'habituate' to their condition can be delivered through TRT. To understand how TRT works, it is important to understand tinnitus in greater detail. Tinnitus can be divided into two components.

- The first component is the auditory component, or the perception of the tinnitus (arises from the inner ear and auditory centers in the brain).
- The second component is the non-auditory component and this refers to the 'bothersome' nature of tinnitus. This non-auditory component arises from the limbic system (the emotional center of the brain) and the autonomic nervous system (the brain's 'alert system' designed to give the message to the individual of 'fight' or 'flee' from a dangerous situation). When the limbic system is activated by the tinnitus, the individual may feel a sense of extreme discomfort or panic

TRT can help a person 'habituate' to their tinnitus. To 'habituate' to something means to grow accustomed to it. To habituate to tinnitus means to reach a state of mind where there is no longer a negative emotional response to the tinnitus.

Tinnitus Retraining Therapy is delivered by Audiologists, who have received specialized training in this therapeutic model. TRT includes:

- **Directive Counseling:** Intensive client education about the auditory mechanism and the role of the brain plays in tinnitus perception. With education, the tinnitus will be 'demystified'. This will

## ***What's All The Noise in My Head? Continued***

help reduce distress and anxiety about the tinnitus.

- **Sound Therapy:** Use of ear level or table-top sound generators and/or hearing aids to provide continuous stimulation of the auditory system to interfere with the perception of tinnitus. This would also include the use of environmental sounds. This will also help reduce distress and anxiety about the tinnitus.

**Time:** It takes time for the brain to habituate to the perception of tinnitus. Most clients report a noticeable improvement is as little as 6-8 weeks. The duration of the TRT program can last between 16 – 24 months.

Regardless of the cause of the tinnitus, with or without hearing loss, the success rate of TRT is 80%. This is the highest success rate of any treatment or therapy currently available. The effects of TRT are long-lasting and there are no side effects.

If you have difficulty understanding speech or following a conversation in background noise, if sounds seem muffled or you are suffering from tinnitus – you are probably experiencing hearing loss. Make an appointment with an audiologist to get your hearing checked and get advice on how to manage your hearing loss and how to prevent more from occurring. Whether you need a hearing aid, assistive listening device, tinnitus therapy or strategies for communication, an audiologist can help you get reconnected to the world around you.

For more information on tinnitus visit the Canadian Hearing Society website at [www.chs.ca](http://www.chs.ca)

## In Memoriam

### *In Memoriam of ANAC Members*

*Brian Fox, long time member*

*Jack A. Price, long time member*

*Ruby Gale, long time member*

*Richard Garossino, founding member of ANAC*

*There's a face we shall always remember,  
A voice we shall always recall,  
A memory to cherish forever,  
Of one so dear to us all.*



## A Heartfelt Thank You to ANAC's 2014 Donors

*Dr. Ryojo Akagami*  
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### In Memory Of

*Richard Garossino*  
*John Frederick Parker*  
*Richard Vallee. Sr*

### In Honor Of

*Lisa Bauer & Dan Baldwin*  
*Patrick Nakagawa*  
*Cyrelle and Bernard Shoub*

### And to our Corporate Donors

*Ontario Power Generation*  
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**Thank you to all donors and members for their continued support. Donations are accepted on ANAC's website [www.anac.ca](http://www.anac.ca), by contacting ANAC at 1-800-561-2622, or [info@anac.ca](mailto:info@anac.ca)**

**And last but not least....  
Thank You to the 2014 Symposium Donors**

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Pizza Pizza

## Donating Made Easy – Charity Car Removal

Looking for an easy way to get rid of your old car? ANAC has recently become part of the Donate A Car program meaning that we can now receive vehicle donations of cars, motorcycles, SUVs and boats! Donate A car will remove junk vehicles (even those that no longer run) for free or recycle newer vehicles while providing a tax receipt. If you want free towing of your old car, please visit [www.donatecar.ca](http://www.donatecar.ca) and choose ANAC to make the donation to.



## Member Resources

Did you know.....ANAC has many resources for newly diagnosed and post-operative management options for acoustic neuroma patients, in the form of e-booklets?

The following e-booklets are available to you:

- Patient Resource Handbook
- Eye Care
- Headache
- Hearing Loss
- Improving Balance
- The Facial Nerve

Please contact the National Office to have your copies emailed to you.

## Invitation to Members

*Inspire others and share your experience*

We invite members to share their personal stories with other members. Your story should include how you were diagnosed, pre-during-post stages of your treatment/experience. The support you received from family and friends as well as lessons you have learned.

To submit your story, contact: Theresa Forson, National Coordinator.

## 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 cities across Canada.

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](mailto:info@anac.ca) to speak with other patients in your region.

### **British Columbia: Courtenay / Nanaimo**

For further information contact:  
Evalyn Hrybko at 250-282-3269 or  
email [wehrybko@saywardvalley.net](mailto:wehrybko@saywardvalley.net)

### **Ontario: Kitchener / Waterloo**

For further information contact:  
Linda Darkes at 519-696-3445 or  
email [pdarkesc659@rogers.com](mailto:pdarkesc659@rogers.com)  
Helen Horlings at 519-954-5581 or  
email [healto@rogers.com](mailto:healto@rogers.com)

### **Ontario: Toronto**

For further information contact:  
Lynda Nash at 416-282-0036 or  
email [lynda\\_lu123@sympatico.ca](mailto:lynda_lu123@sympatico.ca) or  
Kathryn Harrod at 905-891-1624 or  
email [tim.harrod@sympatico.ca](mailto:tim.harrod@sympatico.ca)

### **Ontario: London**

For further information contact:  
Margaret Dodgson at 519-451-3443 or  
email [dodgsonm@rogers.com](mailto:dodgsonm@rogers.com) or  
Lorraine Swanson at 519-668-7737 or  
email [lor.anac@yahoo.ca](mailto:lor.anac@yahoo.ca)

### **Ontario: Ottawa**

For further information contact:  
Contact: Nick Dinelle 613-831-2426 or  
email [ndinelle@rogers.com](mailto:ndinelle@rogers.com) or  
Facebook: ANAC OTTAWA/OUTAOUAIS

### **Manitoba: Winnipeg**

For further information contact:  
Faye Gorenson at 204-762-5611 or  
email [fsg@mts.net](mailto:fsg@mts.net)

### **National Chapter**

For further information contact:  
Contact: Nick Dinelle 613-831-2426 or  
email [ndinelle@rogers.com](mailto:ndinelle@rogers.com)

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 Alberta, British Columbia, Saskatchewan, Quebec and all East Coast Provinces. If you are be interested in helping establish a new group in an under serviced area, please contact Theresa Forson at the National Office for an information package and support.

[info@anac.ca](mailto:info@anac.ca)

**1-800-561-2622**

# Caring Sharing Supporting!

***Acoustic Neuroma is a benign brain tumour affecting the functions of the inner ear. It is often misdiagnosed or undetected. If any of the following symptoms persist, consult your physician.***

- ***One-sided deafness, gradual or sudden***
- ***Balance problems or unsteady gait***
- ***Facial numbness, tingling, or spasms***
- ***Headaches***
- ***Dizziness***
- ***Visual disturbances***
- ***Tinnitus (ringing or buzzing in the ears)***



***Acoustic Neuroma Association of Canada***

***Association pour les Neurinomes Acoustiques du Canada***

The Acoustic Neuroma Association of Canada (ANAC) is a peer support group. Many who face and undergo removal of Acoustic Neuroma and other benign tumours involving the cranial nerves have questions, concerns, and physical and emotional adjustments. Membership in a group of those with similar experiences can be helpful to patients as well as family members and interested medical personnel.

As a registered non-profit organization, ANAC strives to:

1. Provide support and information to patients.
2. Furnish information on patient rehabilitation.
3. Promote and support medical research.
4. Educate the public to promote early diagnosis.

The Connection is prepared and edited by Jennifer Wong, ANAC Board Director. Please forward all comments, feedback and story ideas to [info@anac.ca](mailto:info@anac.ca)

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