

The

Connection



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**Association
pour les
Neurinomes
Acoustiques du
Canada**

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Summer Edition



Acoustic Neuroma



Association of Canada

Inside this issue:

A Friend By My Side	2
Hearing Ear Guides	3
Welcome to the Medical Advisory Board	4
Being Supportive and Accessible	6
ANAC Chapters	7

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 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 or contact Chapter Leaders:

Lynda Nash at (416) 282-0036 or by email at lynda_lu123@sympatico.ca

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

Bilateral Acoustic Neuroma and Hearing Ear Dog Guides

A Friend In Deed Always by My Side

By: Debbie & Bart MacDonald



I have NF2, sometimes called bilateral acoustic neuromas. It is an inherited condition and I come from a large family which has had NF2 traced back for several generations. (Our family participated in a US National Institutes of Health study on NF2, beginning when I was 16 and continuing for almost 20 years.) I was diagnosed at age 18 and had my first AN surgery at age 29 (I am currently 59). Nine years later I had AN surgery on the other side and became totally deaf. To date, I have had 5 AN surgeries, a shunt put in (and a repair to the shunt), plus three rounds of radiation, including Gamma Knife.

For many years, being deaf was not a significant issue because I was a stay-at-home mom for three active children, and my pet dog was always with me. The children and the dog all kept me 'clued in', so I did not miss much. But after thirteen years my dog died and my children were beginning to leave home. I

was often by myself and, for the first time, realized what life was really like to be deaf ...SCARY!!!

I love to cook and bake, but I burnt many things because I forgot about the timer. I'd be startled by people suddenly appearing – when I did not even know they were in my home! On my long walks in the woods, I felt so alone. I knew I needed help, so I contacted the Lions Foundation of Canada Dog Guides about getting a Hearing Ear Dog. My first HED dog, Merrill, was a large, goofy Standard Poodle who instantly won my heart. She was my constant companion. Very quickly all my insecurities disappeared. Also, no more burnt cookies, unexpected visitors, and so much more. My family liked calling my name and having her lead me to them. I liked not being hit by Nerf balls when my attention was needed! Merrill was totally my responsibility and we were a terrific team. Sadly, in 2011 she suddenly died of a fast-growing cancer.

The Lions Foundation quickly provided me with another poodle to be my new helper. Bart is a wonderful partner who keeps my life interesting. Dog Guides is amazing at matching people with dogs that suit our different needs and lifestyles.

Because of the Human Rights Act, Bart is allowed to come with me almost everywhere. I do lead a quiet life but we go shopping, to church, to weddings, funerals, graduations, hospitals, restaurants, - everywhere! For someone with a disability, a dog guide is a priceless gift of independence.' These are practical, working dogs who have special privileges (i.e. can go where other dogs can't) and make a big contribution to independence (a very important issue when you have disabilities!) I will forever be grateful to the Lions Foundation Dog Guides for gifting me with such trusted and helpful friends who are always by my side!!



Friends; Lend Me Your Ears...

By: Susan Johnston

Susan is a long time ANAC member with NF2/Bilateral Acoustic Neuromas and is profoundly deaf. Susan, and her husband Randy, have volunteered with Dog Guides for the past three years.

ANAC members may be interested in the Lions Foundation of Canada's Hearing Ear Dog Guides program. Dog Guides is probably best known for its founding program, the Canine Vision Canada Dog Guides, established in 1985 to help people who are blind or visually impaired. Over the years, Dog Guides has added five additional programs including (beginning in 1988) the Hearing Ear Dog Guides for the deaf and hard of hearing.

Hearing Ear Dogs (HED) are trained to detect sounds their handlers are unable to hear on their own. The dogs have been taught to distinguish sounds, make physical contact with their handlers and lead them to whatever is making the noise; be it someone at the door, an alarm clock or other timer (e.g. stove or laundry), or a ringing telephone. The dogs are also trained to alert their handlers to a fire alarm. Hearing Ear Dog Guides give their handlers an increased sense of security and ease by knowing that they will always have a link to the world of sound through their Dog Guide.

Currently Dog Guides graduates 20-30 HED teams a year. The waiting list ranges from 6 months to a year. Once an application has been accepted, applicants are processed on a first-come; first-served basis – with the exception that handlers whose current dogs are retiring have priority. Application forms can be found on the Dog Guides website - (<http://www.dogguides.com/forms/HEDForm.pdf>). You will also need your doctor to fill out a medical report form and include a recent (within the past 12 months) audiology report. Following acceptance, Dog Guides trainer will visit the applicant's home to gather lifestyle information used to match the applicant with an appropriate dog. Future Dog Guide puppies go through a 10-12 month foster period with a family, learning basic obedience and becoming well socialized through exposure to a variety of experiences. The dogs then go through a 4-6 month training period to learn the specific skills needed to work with their handler.

The dogs (and a two-week training period for the handler at the Dog Guides training facility in Oakville, Ontario) are provided at no cost to eligible Canadians from coast to coast despite costing \$25,000 to train and place. The Foundation relies on donations from individuals, service clubs, foundations and corporations and does not receive any government funding. The on-going cost of the dog's care (e.g. food, vaccinations, and other medical expenses if the need arises) is the responsibility of the handler.

Note that due to the importance of the bond between a Hearing Ear Dog Guide and their handler, it is Dog Guides' policy that there be no other dogs living in the immediate household. If you currently have a dog, you may apply for a Hearing Ear Dog Guide, however if you are accepted you must rehome your pet dog before Dog Guides can place a Hearing Ear Dog Guide.

For more information on the Hearing Ear Guide Dog Program please contact (800) 768-3030 or visit them on the web at www.dogguides.com



Susan Johnston with HED trainer Angela Bentivegna

ANAC Welcomes New Members to the Medical Advisory Board



Michael Tymianski MD PhD FRCSC
Head, Division of Neurosurgery, UHN
Professor, Dept. of Surgery (Neurosurgery), University of Toronto
Research Chair (Tier 1) in Translational Stroke Research
Sr. Scientist, Toronto Western Hospital Research Institute
Medical Director, Neurovascular Therapeutics Program, UHN

Dr. Tymianski graduated from the University of Toronto, Faculty of Medicine in 1987, and became a Fellow of the Royal College of Physicians and Surgeons of Canada in 1995.

Dr. Tymianski is the Head of the Division of Neurosurgery, Toronto Western Hospital, University Health Network.

He is also a Professor in the Departments of Surgery and Physiology at the University of Toronto, Medical Director, Neurovascular Therapeutics Program, University Health Network, Director of the Neuroprotection Laboratory at the Toronto Western Research Institute, Program, and is the recipient of a Tier 1 Canada Research Chair in Translational Stroke Research.

As a practicing neurosurgeon, he specializes in cerebrovascular and skull base neurosurgery, with an interest in the surgical treatment of acoustic neuromas. Dr. Tymianski is part of a multi-disciplinary team in which all acoustic neuroma patients receive a comprehensive assessment. Different treatment options are discussed, which may include observation (regular MRI screening), microsurgical removal of the tumor, or radiosurgery. If surgery is chosen, he often works in conjunction with an experienced team of neuro-otologists.

Dr Tymianski is a frequent speaker at international neurosurgical and scientific conferences. He was recently a Guest Speaker at the Acoustic Neuroma Society conference in Toronto in October 2014, a one day seminar that provided an educational experience for patients, families and primary health care professionals.

As Senior Scientist the Toronto Western Research Institute, Dr. Tymianski's research has focused on the understanding of the cellular and molecular mechanisms of neuroprotection and neurodegeneration. For the past 23 years, he has focused on making fundamental scientific discoveries, and then supervising their translation from cell-based experiments through to animal and even human studies.

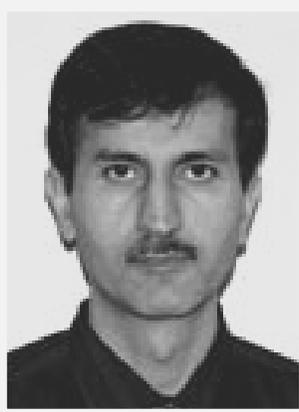
ANAC Welcomes New Members to the Medical Advisory Board



Alireza Mansouri MD
Neurosurgery Division, University of Toronto

It is an honour and pleasure to be associated with the ANAC! I am currently a Neurosurgery resident physician. I am in the process of completing a master's degree in clinical epidemiology and my interests include quality of life measures and predictors of patient-important outcomes. Upon completion of residency, I will be pursuing a fellowship in neuro-oncology and skull base surgery. I look forward to our future interactions!

Regards, *Alireza*



Farhad Pirouzmand, MD, MSc, FRCSC,
Neurosurgeon, Assistant Professor of Neurosurgery, University of Toronto

Dr. Pirouzmand completed his residency in the neurosurgery training program at the University of Toronto in 1998. He then completed a year of fellowship in skull base and reconstructive surgery and a year of fellowship in spinal trauma and peripheral nerve surgery. Prior to his joining the neurosurgical faculty at the University of Toronto, he was the Program Director of Neurosurgery at the University of Saskatchewan. Dr. Pirouzmand has completed a Masters in Epidemiology from the University of Saskatchewan. His thesis was on skull topographic organization. His main areas of interest are skull base, acoustic neuroma surgery, peripheral nerve, and orbital reconstructive surgery. He is currently involved in coordinating clinical trials in neurosurgery at Sunnybrook Health Sciences Centre. Thank you, *Farhad Pirouzmand*

2015 Medical Advisory Board

Chair

Dr. Gelareh Zadeh (Toronto). *Neurosurgeon, Assistant Professor, Clinician Scientist, Neurosurgery*

Members

Dr. Alireza Mansouri (Toronto). *Neurosurgery Division, University of Toronto*

Dr. Anthony Kaufman (Winnipeg). *Neurosurgeon, Associate Professor, Neurosurgery*

Dr. David Roberge (Montreal). *Head Department of Radiation Oncology, University of Montreal*

Dr. Farah Pirouzmand (Toronto). *Neurosurgeon, Assistant Professor of Neurosurgery, University of Toronto*

Dr. Igor Barani (UCSF, California). *Assistant Professor, Radiation Oncology, Practice Focus: Gamma Knife, Cyber Knife, Radiosurgery*

Dr. Ivan Radovanovic (Toronto). *Scientist, Toronto Western Research Institute, University Health Network, Assistant Professor of Surgery, Faculty of Medicine, University of Toronto*

Ms. Joanne Dorion PT (Sunnybrook). *Personal Best Independence & Wellness Centre, Sunnybrook Health Sciences Centre*

Dr. John Rutka (Toronto). *Professor ENT/Skull Base Surgeon, Toronto General Hospital*

Dr. Joseph Chen (Toronto). *Chief, Department of Otolaryngology - Head & Neck Surgery*

Dr. Mike Tymianski (Toronto). *Head, Division of Neurosurgery, UHN Professor, Dept. of Surgery (Neurosurgery), University of Toronto, Research Chair (Tier 1) in Translational Stroke Research, Sr. Scientist, Toronto Western Hospital Research Institute Medical Director, Neurovascular Therapeutics Program, UHN*

Being Supportive and Accessible



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

Offering support groups is an important function for ANAC chapters. Whether individuals are newly diagnosed, on “watchful waiting”, contemplating treatment or have completed a procedure, ANAC is there to be a trusted resource, voice of experience and source of comfort.

Single-sided deafness (SSD) is a usual consequence of having an acoustic neuroma. SSD can be quite stressful to manage. Being deaf in one ear presents a variety of challenges, most notably difficulty in determining the direction of sound. Another issue which affects communication is the “head shadow effect.” Sounds that originate from the side of the deaf ear actually fall in the shadow of the head. Vowel sounds which have longer wave lengths may still travel from the deaf side to the hearing side, but consonants which have a shorter wavelength and carry the most meaning for speech and conversation, don’t do as well in terms of making their way from the deaf ear around

the head to the hearing ear. This can cause a great deal of frustration for the individual with SSD especially when trying to communicate in the presence of background noise.

Directionality (or sound localization) is an important aspect of managing communication and environmental cues. Interacting in circular group meetings can be difficult even if participants are speaking one at a time and even worse if distance is a factor for large circular discussions. Whispered communication into the deaf ear in quiet environments is also problematic.

For the above reasons, we need to ensure that our support groups encourage communication and are accessible to the participants. To address accessibility, the Toronto chapter tried out a Simeon portable sound field FM system. The Simeon System includes one body-worn transmitter with a boom microphone and one pass-around transmitter/microphone. Speech from the microphones are transmitted wirelessly on FM waves to a portable high fidelity speaker which can be placed anywhere in the room. The Simeon system made a huge difference at our chapter meeting and everyone was able to hear and participate much more effectively than in previous meetings.



Through the gracious donations of individuals attending a fundraiser event hosted by ANAC President, Lyna Newman, a Simeon System was purchased for the Toronto ANAC chapter. The system was acquired through the Canadian Hearing Society at a discounted rate.

I would encourage all chapters to take a close look at how accessible their meetings are and at the very least, ensure good communication strategies are utilized. For anyone interested in learning more about the Simeon System, do not hesitate to contact me at rbanks@chs.ca

Support Groups Across Canada

People diagnosed with an acoustic neuroma and their loved ones, often find help through the helpful nature of an acoustic neuroma support group. Support groups are a gathering of people who share emotional support and information through similar life experiences. Within the safety of a support group, many people are able to share the details of their past experience, fears, concerns about the future, and the day-to-day challenges encountered. Acoustic Neuroma Support Groups are located across Canada in the cities / regions shown below. For more information on meeting times and locations, please contact the Chapter Leaders in your area.

Individual support is also available through the Acoustic Neuroma Association of Canada's Peer Database Registry. For more information on connecting with a Peer Support Volunteer from the registry, please contact the National Office at 1-800-561-2622 or info@anac.ca.

Alberta: Provincial

Contact: Mary Jane Hradowy
Phone: (587) 216-4448
Email: maaavelouse@me.com

British Columbia: Courtenay / Nanaimo

Contact: Evalyn Hrybko
Phone: (250) 282-3269
Email wehrybko@saywardvalley.net

Manitoba: Winnipeg

Contact: Faye Gorenson
Phone: (204) 762-5611
Email: fsg@mts.net

Ontario: Kitchener / Waterloo

Contact: Linda Darkes
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Email pdarkesc659@rogers.com
Contact: Helen Horlings
Phone: (519) 954-5581
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Ontario: London

Contact: Margaret Dodgson
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Phone: (519) 668-7737
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Contact: Lynda Nash
Phone: (416) 282-0036
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Contact: Kathryn Harrod at 905-891-1624
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Ontario: Ottawa

Contact: Nick Dinelle 613-831-2426
Email: ndinelle@rogers.com
Facebook: ANAC OTTAWA/OUTAOUAIS

National Chapter

Contact: Nick Dinelle
Phone: 613-831-2426
Email 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 British Columbia, Saskatchewan, Quebec and all East Coast Provinces. If you are interested in helping establish a new group in an under serviced area, please contact the National Office at (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

ANAC

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