The

Symposium Edition



A Publication of the Acoustic Neuroma Association of Canada

Association pour les Neurinomes Acoustiques du Canada

www.anac.ca

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November 2014

ANAC 2014 Symposium —a weekend to remember

The night before the symposium, there was a meet and greet held at The Marriott hotel located in the heart of downtown Toronto. It was a chance for newly diagnosed members to make their introductions, old members to reconvene, and board members to meet those who are at the core of ANAC.



ANAC members mingling with ANAC President and Board Members

What a GREAT event!

ANAC's symposium was a huge success with over 50 in newly diagnosed attendance: members. AN patients. neurosurgeons, otolaryngologists, resident physicians, and AN researchers. The event was hosted at the Toronto Western Hospital, which specializes in neurosurgery and was actually one of the first Canadian hospitals to use the Gamma Knife procedure. Our day started off with a continental breakfast and a chance to meet and greet with ANAC's Board of Directors, guest speakers and both old and new members alike. Newly elected president Lyna Newman gave a warm welcome to the crowd and introduced the jam packed day.

The day included presentations on the management of vertigo, facial rehabilitation techniques, and the various options to newly diagnosed patients: A general rule of thumb suggested that 'Watch and Wait' is the preferred method if the tumour is under 1 cm, Gamma Knife radiation and other types of radiation if the tumour is under 2.5 – 3 cm, and a discussion about the two most common types of surgery, translabyrinthine and suboccipital.

The Big Day...

The symposium featured Communication Access Real-Time Translation (CART) used to close-caption the entire event for audience members with hearing difficulties. Attendees had the chance not only to learn from leaders in their field but also to interact with the speakers through question and answer periods and audience led discussions with the medical panel and ANAC's medical advisory board.



Medical panel and audience Q&A period

Thanks to our amazing symposium prize sponsors, we raised an impressive amount of funds with our raffle draw! Altogether, the success of ANAC's 2014 Symposium astounded and surpassed the expectations of the organizing committee and received overwhelmingly warm praise from both speakers and guests. We have already been invited back to the Toronto Western Hospital for our next symposium!

Notes from the Annual General Meeting

After a full day of presentations and mingling, ANAC's 2014 Annual General Meeting was held and open to all members. In summary, since ANAC's 2012 AGM, Theresa Forson was welcomed as the National Coordinator, Lyna Newman was elected as President, and John Lalley as Vice- President. We were also happy to announce Nicholas Kucharew and Rex Banks as new members of the board of directors, in addition to the re-election of Americo Meneguzzi, Galareh Zadeh, Jennifer Wong, Cora Hennel- Greer and Chris Grant.

Chris Grant, John Lalley, Cora Hennel-Greer, Americo Meneguizzi, Lyna Newman & Nicholas Kucharew

Theresa Forson & Jennifer Wong





Notes from ANAC's Strategic Plan meeting in June 2014 were presented to members. The areas that ANAC will be focusing on in the current term include a website overhaul to include active forums, a Canada-wide directory of medical professionals and online membership renewals. Other areas of action included membership value proposition and increasing awareness of ANAC members' access to multidisciplinary team (MDT) reviews.

ANAC's 2014 Board Members



Lyna Newman, FCIP, CRM, CHRP - Elected for 3 year term

Lyna brings a broad spectrum of experiences. The first 10 years of her insurance career focused on the technical underwriting side - primarily underwriting and brokering Fortune 500 accounts. For the past decade, Lyna was most recently Vice President, Human Resources and Operations with RRJ Insurance Group where she helped integrate the HR and IT elements of several acquisitions.

From 2001 to 2011, Lyna joined the Board of Directors for WICC, a charity whose mission is to raise funds to support cancer

research, exclusively for the benefit of the Canadian Cancer Society (CCS). In the early years, she assumed the position of Executive Director where she established numerous operational procedures for this fast-growing charity.

In 2011, Lyna was honored with the "Lew Dunn award" for distinguishable service as a volunteer. For 10 years, Lyna taught at the Insurance Institute of Ontario, and for 5 of those years, was Chairperson of the Faculty Committee and Ethics Committee. In 2009, Lyna was awarded the "Fellow of Distinction" by the CIP Society, Insurance Institute of Canada.

In 2013, Lyna joined the Board of Directors for the Acoustic Neuroma Association of Canada (ANAC). In 2014, she assumed the role of President for ANAC.

Americo S. Meneguzzi CA. CPA. - Elected for 2 year term

Americo, a Chartered Accountant, spent several decades working for the Metropolitan Separate School Board. Before retiring he held the position of Deputy Director of Education, Business Administration, Treasurer and Assistant Secretary.

He has voluntarily contributed to a variety of social, educational and religious organizations providing accounting, tax clinics and continues to act as the Secretary/Treasurer for ANAC.



Currently, Americo is semi-retired and a self-employed, business consultant and developer. He is married with three children and is the proud grandfather of seven grandchildren.

Meet ANAC's 2014 Board Members



<u>Dr. Gelareh Zadeh</u> MD, PhD, FRCS(C) – Elected for 2 year term

Dr. Gelareh Zadeh completed her Neurosurgery and PhD training at University of Toronto in 2006. Following a Cancer Care Ontario funded fellowship at University College London Dr. Gelareh Zadeh started on staff as a clinician scientist neurosurgeon, first at The National Hospital for Neurology and Neurosurgery at University College London UK and subsequently in 2008 started as a CIHR Clinician-Scientist and neurosurgeon at the Toronto Western Hospital and

University of Toronto. Her clinical and research focus is in neuro-oncology, with specialization in skull base surgery, acoustic neuromas/vestibular schwannomas, and minimally invasive endoscopic approaches to anterior skull base, sellar and parasellar lesions. She is also an active member of the Gamma Knife radiosurgery program. She has focused subspecialty multidisciplinary clinics for management of brain metastases, skull base/pituitary and neurofibromatosis clinic at University Health Network. Dr. Zadeh has an active peer review funded research laboratory focused on molecular mechanisms of tumor vascularization and response to radiation therapy. Her lab is also focused on understanding the genetics and molecular profile of skull base tumors, specifically focusing on vestibular schwannomas and meningiomas. Her clinical research is focused on establishing clinical trials for patients with brain metastases and vestibular schwannomas.

Chris Grant - Elected for 2 year term

Chris was diagnosed 9 years ago with a small 0.9cm tumor and has been fortunate to be able to report very little growth since diagnosis. His hearing however, as a result, greatly diminished in his right ear but is fortunately manageable.

He has been in construction for 33 years and has always been self-employed, which has allowed him the time to volunteer with ANAC for the past four years with the support of his wife, two stepdaughters and grandson.

Chris has always enjoyed giving back and watching the organization grow through the years. He looks forward to what the future has in store for the organization.



Meet ANAC's 2014 Board Members



Cora Hennel-Greer - Elected for 2 year term

Cora has a Masters Degree in Business Administration and has been an active volunteer for more than 25 years including day care, junior achievement and sports. She is a mother of four adult children. She and her partner Wayne have been together for more than 25 years.

In addition to her role on the ANAC Board, Cora spends time in the family business while waiting to return to employment at Wilfrid Laurier University.

Cora has been in the post-secondary school system since 1985

in various positions: Entrepreneurship Advisor, Instructional Designer, Training Consultant and Program Coordination. Cora also enjoys travelling, reading and her dog Skye. Cora joined the Board of Directors in 2011.

Nicholas Kucharew, MBA, CPA, CMA, PMP, CISA, CISM, CRISC – Elected for 4 year term

Nick brings experience in not-for-profit, accounting/financial systems, and especially in Information Technology (IT), where he has spent more than twenty-five years passionately learning everything he can about the field.

Nick is currently undertaking Information Technology as it relates to ANAC's website and online presence. He is optimistic that he can significantly improve and enhance both the look



and feel of ANAC's website, and the functionality of it with his goal to provide a rich experience for visitors and give extra value to ANAC's membership.

Nick is also an acoustic neuroma patient, whose AN journey began in June 2011. He regularly attends the Toronto Chapter Meetings for support and information.

Meet ANAC's 2014 Board Members



Jennifer Wong - Elected for 3 year term

Jennifer has been working as an EKG technician since graduating from the University of Toronto as a Cell & Molecular Biology major with a minor in Sociology. She will be attending the University of Waterloo's PharmD program in Winter 2015. Prior to joining ANAC's Board of Directors in 2013, Jennifer has served on the Markham Terry Fox Run's donations committee in 2011 and as a volunteer notetaker for the University of Toronto's Accessibility Services during undergrad.

Jennifer also continues to hold the Luminary Sales and Operations chair position at the Canadian Cancer Society's Relay for Life (North York) for her 3rd year. There, she led the

virtual luminaries initiative that is now used at other Relay for Life events across Toronto and included in the volunteer handbook.

<u>John Lalley</u> – Elected for 4 year term

John is a dynamic and innovative manager with expertise in marketing and business strategy, web design, user and customer experience, social marketing, web accessibility and developing technology. John has been a marketing manager with the Canadian Hearing Society (CHS) since 2013 in a broad role that encompasses digital and traditional marketing, business development and vendor management.



He was diagnosed with a 5.5cm acoustic neuroma in December 2004 and had surgery at Sunnybrook in January 2005. From the start, he was open to sharing his story with others and connecting to the acoustic neuroma community. You can read about the details of his diagnosis, surgery and short term recovery on his blog, The Centre of the Rind. John is passionate about raising acoustic neuroma awareness, issues related to Single-Side-Deafness, hearing aids and adaptive technology. His portfolio on the board is membership marketing and he will be working to add value and enhance the experience and engagement with current ANAC members, as well as working on increasing membership.

Finally, John is a Juno award-winning musician and has played with a multitude of Canadian artists; he continues to record and perform. He is also a sponsored kitesurfer and can be found on the waters of the Great Lakes when conditions allow.

Meet ANAC's 2014 Board Members



.Rex Banks - Elected for 4 year term

Rex Banks has been an audiologist for 25 years and is the Chief Audiologist and Director of Hearing Healthcare at The Canadian Hearing Society. Rex received his M.A. in Audiology from The University of Tennessee: B.A. in Communication Disorders from The University of Mississippi; and is expected to complete his Doctor of Audiology degree from A.T. Still University of Health Sciences Past adjunct university appointments include in 2015.

Western Kentucky University and Nova Southeastern University.

Some of Rex's advocacy work includes:

- ANAC Toronto chapter support group facilitator
- √ President, Board of Directors for the Canadian Academy of Audiology
- Board of Directors, Ontario Association of Speech Language Pathologists and Audiologists
- Appointed to the Health Professionals Advisory Committee (HPAC) for the Toronto Central Local Health Integrated Network (LHIN).
- Canadian Clinical Director for the Ontario Special Olympics Healthy Hearing/ Healthy Athletes Program
- Member of the Toronto Go Transit Accessibility Council
- Appointed to the Broward County Florida Advisory Council for Persons with Disabilities
- Director of the Broward County United Way Success By Six Hearing Screening Project

Rex has made numerous community presentations and is often consulted by the media on a wide range of issues pertaining to hearing loss. Proficiency, enthusiasm and compassion have always been Rex's guiding principles in serving both his clients and his profession.

GIVINGTUESDAY

This holiday season, ANAC has partnered with Giving Tuesday (www.givingtuesday.ca) which will take place on December 2, 2014. Giving Tuesday is the "national opening day of the giving season"- a day where companies and individuals come together to celebrate giving and volunteering by donating to a charity of their choice. Since it began, it has been featured on CTV news and The National Post. Last year, CanadaHelps.org - a website for online donations to charity- experienced a 91% increase in giving!

An an official partner of Giving Tuesday, we encourage you to consider making a donation to ANAC. We greatly appreciate your continued support as members, and belief in ANAC's mission of providing information about the treatment of acoustic neuromas, public awareness of the cause and promoting research for treatment. This holiday, give the gift that fosters ongoing involvement and awareness of acoustic neuroma across Canada.

For more information on how you can donate to ANAC, please contact the National Coordinator at 1-800-561-2622 or info@anac.ca

Regional Support 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.

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.

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.

British Columbia: Courtenay / Nanaimo

For further information contact: Evalyn Hrybko at 250-282-3269 or email wehrybko@saywardvalley.net

Ontario: Kitchener / Waterloo

For further information contact: Linda Darkes at 519-696-3445 or email <u>pdarkesc659@rogers.com</u> Helen Horlings at 519-954-5581or email <u>healto@rogers.com</u>

Ontario: Toronto

For further information contact: Lynda Nash at 416-282-0036 or email <u>lynda lu123@sympatico.ca</u> 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

Ontario: Ottawa

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

The Ottawa/Outaouais Chapter is currently inactive. The Chapter Leader is available for support and information.

Manitoba: Winnipeg

For further information contact: Faye Gorenson at 204-762-5611 or email fsg@mts.net

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

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.

ANAC

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Please forward all comments, feedback and story ideas to info@anac.ca