

The

# Connection



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**Association  
pour les  
Neurinomes  
Acoustiques du  
Canada**

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

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## **Those Devastating Words**

*By: Nicholas L. Dinelle*

I will never forget those devastating words; "You have an acoustic neuroma." At first I just sat there, expressionless trying to understand what he just said. Then I felt nauseous and thought that I was either going to be sick to my stomach, pass out or both! My world had just fallen apart. After a few minutes, the vertigo passed, I drank some water and I once again was capable of communicating. Since this was a routine follow up to a recent MRI, I saw no need to have my wife accompany me to the appointment. As a result, I was alone and too dumbfounded to comprehend the information that the doctor was sharing. All I remember hearing is that I had a brain tumour; everything else was a blur. And so my acoustic neuroma journey began.

Two years later the nasty little "alien" was surgically excised using the translabyrinthine approach. It was 2003 and at that time gamma or cyber knife was not readily available. Besides, after two years of waiting for treatment the tumour had grown exponentially so surgical excision was the only viable option; when you're referring to an acoustic neuroma, size does matter!

I discovered the forums on the ANAC website about six months after my surgery. I met a group of daily contributors who became fast friends providing support, guidance, information and encouragement to anyone who joined the forum.

*"Whatever we think about and thank about we bring about."* quotes Dr. John F. Demartini former chiropractor and current American researcher, best selling author, international educator, and public speaker in human behavior.

When we feel thankful our lives become more satisfying and one can make strides in making things happen.

## Those Devastating Words

We were a diverse group from far and wide; people like Kelly Rama in Winnipeg and Lorenzo Tonti in Ireland. It was ANAC's first virtual support group.

I truly appreciated the support of these new friends but unfortunately, I never got the chance to thank them for helping me to heal both physically and mentally. Nothing lasts forever and the ANAC forums were no exception. Thanks to an invasion of bots on the website ANAC was forced to shut down the forums. By the time the website was up and running again with new security measures, everyone had moved on.



*Nicholas Dinelle*

I continued to visit the ANAC forums, but there were few contributors and none of the old regulars. I understand that ANAC's Board of Directors is working to enhance the value of membership and provide resources such as a new robust website.

I stayed in touch with ANAC acting as a resource for ANAC and others in the national capital region in need of support or a shoulder. Support was initially in the form of emails and phone calls. A lady who I spoke to on the phone asked if it would be possible to meet in person. I met with her and her husband in a nearby Tim Hortons and chatted for more than an hour. From that day on one-on-one face to face meetings became my preferred method of providing support. I continued to meet with people at Tim Hortons as it provided a safe and friendly environment for both parties.

While the one-on-one meetings were successful, I didn't have all the answers and providing follow up answers later was not an ideal solution. First and foremost I wanted to offer support and a shoulder but I realized that I needed help. Since I had been in contact with so many people in the national capital region who had been diagnosed with or treated for an acoustic neuroma, I decided to organize a meeting.

I mailed letters to doctors asking that they post meeting notices in their waiting room, sent emails and phoned those who had previously approached me regarding an acoustic neuroma. The inaugural meeting of the Acoustic Neuroma Association of Canada Ottawa Chapter was held on March 7<sup>th</sup>, 2006.

Despite the status of the local support group, I am still a strong believer in the concept. There is a place in the health care system for support groups to fill the gap between the time when you hear those devastating words, receive treatment, recuperate and have resumed your normal life.

## Those Devastating Words

It doesn't matter if those devastating words are acoustic neuroma, cancer, Alzheimer's or any other illness, no one should have to go through it alone. It is not only the patient who benefits from a support group. Spouses, parents, siblings, children and close friends are all affected by the illness and they too may need support and a shoulder to cry on.

Often AN patients are not only coping with their illness but also dealing with the alienation of loved ones, callous co-workers and employers. Symptoms of an acoustic neuroma are invisible and without any outward signs people tend to become frustrated or upset as they find it hard to believe that you are truly ill. After attending a support group meeting, a wife or husband will have a better understanding of what their spouse is dealing with and have an opportunity to interact with other spouses who may share their frustrations.

I can think of no one who is in more need of a support group than the spouse of an Alzheimer's patient. Their lives are consumed by the round the clock care that they provide to someone who will eventually regard them as a stranger. They live in near total isolation not daring to leave their spouse unattended day or night. By the time that their spouse is institutionalized, they too are broken and exhausted; a shell of their former selves.

If you have access to a local support group, please attend a meeting; you will be pleasantly surprised. If there is no support group in your community, reach out to others who would like to start a group. Meetings can be held cost free in any number of locations including restaurant, Tim Hortons, municipal buildings, libraries, churches, etc. A support group can be set up without any cost and will be well worth your time and effort.

I believe in the saying that it takes a village to raise a child. But I also believe that regardless of how young, old, rich or poor we are, we all still need that village and we should strive to make that village strong. At one time or another, we all need that shoulder to cry on and the occasional hug.

### What's New

#### **"The BRAIN Initiative"**

*With nearly 100 billion neurons and 100 trillion connections, the human brain remains one of the great mysteries in science and one of the greatest challenges in medicine. . . Despite the many advances in neuroscience in recent years, the underlying causes of most neurological and psychiatric conditions remain largely unknown, due to the vast complexity of the human brain.*

(National Institutes of Health, June 2014)

## **“The BRAIN Initiative”**

Knowledge of how the brain actually works has eluded experts for centuries. It's a fundamental gap in the knowledge that is today holding up the necessary full understanding and means of effective treatment of major neurological disorders such as Alzheimer's and Parkinson's. For acoustic neuroma patients, attempts to deal definitively with problems of tinnitus have been frustrated. Mapping and imaging of neural circuits in the brain is now possible but the crucial next step is still missing: It is crucial to understand how these circuits work to capture the full sense of what is happening in the healthy brain – and what goes awry in disease.

The BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies) has the potential to end the centuries-long search to discover what has been called 'the language of the brain.' "How the brain works and gives rise to our mental and intellectual lives will be the most exciting and challenging area of science in the 21st century," said Dr. Collins, National Institutes of Health Director. "As a result of this concerted effort, new technologies will be invented, new industries spawned, and new treatments and even cures discovered for devastating disorders and diseases of the brain and nervous system."

The NIH efforts on the BRAIN Initiative will seek to map the circuits of the brain, measure the fluctuating patterns of electrical and chemical activity flowing within those circuits, and understand how their interplay creates our unique cognitive and behavioral capabilities. The goals for achieving this vision:

- Identify and provide experimental access to the different brain cell types to determine their roles in health and disease.
- Generate circuit diagrams that vary in resolution from synapses to the whole brain.
- Produce a dynamic picture of the functioning brain by developing and applying improved methods for large-scale monitoring of neural activity.
- Link brain activity to behavior with precise interventional tools that change neural circuit dynamics.
- Produce conceptual foundations for understanding the biological basis of mental processes through development of new theoretical and data analysis tools.
- Develop innovative technologies to understand the human brain and treat its disorders; create and support integrated brain research networks.
- Integrate new technological and conceptual approaches produced in the other goals to discover how dynamic patterns of neural activity are transformed into cognition, emotion, perception, and action in health and disease.

For basic information and current updates, consult the website of the National Institutes of Health (search BRAIN Initiative).

## ANAC Welcomes

### A New Executive Director



*Carole Humphries*

As a director for over 15 years in long term health care settings and the charity and not-for-profit sector including organizations such as the Canadian Bar Association, Institute of Public Administration of Canada and the Canadian Cancer Society, Carole Humphries has established expertise in thought leadership and strategy execution, operations and building new programs.

Her background executing public/patient education initiatives in multi-settings; and past as a nurse clinician working with patients and staff also provides a foundation to help ANAC grow and address the needs of ANAC's members.

"I am thrilled to be part of ANAC," Carole says. "This is an incredible organization that has been providing information and support to people with acoustic neuromas and their loved ones for 32 years. I look forward to continuing ANAC's history of helping people and building a supportive and collaborative community."

### A New Member to the Board of Directors



*Jennifer Fitzpatrick*

Jennifer Fitzpatrick graduated from Brock University with a degree in Political Science, and continued her education with a Post Grad in Fundraising and Resource Development from Georgian College. After spending three months living and working in Accra, Ghana, her passion for travel and fundraising led her to her current position as Donor Services and Operations Coordinator at Free The Children.

Jennifer has also facilitated service-learning trips that focus on building leadership skills with youth and school groups through Free The Children's sister company Me to We.

Jennifer is honored to be welcomed onto the board, and with much excitement and enthusiasm looks forward to growing with ANAC and continuing their great work.

## ANAC Across Canada

### Kitchener-Waterloo

*By: Linda Darkes*

On October 24, 2015, twelve members of the Kitchener Waterloo chapter met at the home of Helen & Tom Horlings. Our group generally meets in the Spring and Fall (3rd Saturday in Apr/Oct) for a time of support and sharing ideas and information and a pot-luck lunch. The guest speaker at our meeting was Shriya Maharaj, Wellness Co-ordinator at the A.R. Kaufman YMCA in Kitchener. She spoke to us about some of the programs offered at the Y which can benefit clients with balance, strength and mobility issues. She demonstrated some simple exercises we can do at home and gave us lots of encouragement.



If you can't attend one of our Saturday meetings, we would be glad to meet you for coffee/chat. Please contact co-chairs **Helen Horlings** ([healto@rogers.com](mailto:healto@rogers.com)) or **Linda Darkes** ([pdarkesc659@rogers.com](mailto:pdarkesc659@rogers.com))

### Toronto

The Toronto Support Group meets every other month from 6:30 PM - 8:30 PM at the Canadian Hearing Society located at 271 Spadina Road, Toronto, ON. The next upcoming meetings are:

**Tuesday January 26, 2016**

**Tuesday March 29, 2016**

**Tuesday May 31, 2016**

For more information on joining the Toronto Support Group, 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)

### A Tip: Itchy Ears ?

*Thanks to Laura S*

Useful Tip from my Audiologist: If your hearing aides make your ears itch as mine do at the end of the day use Aloe Vera gel. She told me to smear some on the end of my little finger and push it in my ear but I use a cotton bud and smear it on the skirt of the domes. There are a number of products on the market. When I investigated, I was horrified at the costs of some. She stated they are just pure Aloe Vera marketed for ears and any pure Aloe Vera gel is fine to use.

Please send your useful tip to Carole Humphries at [info@anac.ca](mailto:info@anac.ca) so we can share with others in the next edition.

## 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](mailto: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](mailto:maaavelouse@me.com)

### British Columbia: Courtenay / Nanaimo

For further information contact:

Evalyn Hrybko at 250-282-3269 or

Email: [wehrybko@saywardvalley.net](mailto:wehrybko@saywardvalley.net)

### Manitoba: Winnipeg

For further information contact:

Faye Gorenson at 204-762-5611 or

Email: [fsg@mts.net](mailto:fsg@mts.net)

Annamaria Palffy at 204-254-4409 or

Email: [palffya@hotmail.com](mailto:palffya@hotmail.com)

### National Chapter, Ottawa

For further information contact:

Contact: Nick Dinelle at 613-831-2426 or

Email: [ndinelle@rogers.com](mailto: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](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)

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](mailto:info@anac.ca)

**1-800-561-2622**



## **Acoustic Neuroma Association of Canada**

### **Caring Sharing Supporting!**

*"The heart of the volunteer is not measured in size but by the depth of the commitment to make a difference in the lives of others." De Ann Hollis*

At this time of the year it is only fitting that ANAC recognize those people who so generously share their experience and talk with others impacted by an Acoustic Neuroma, including those who willingly lead the support groups across Canada. A special note of thanks to: Linda Darkes, Nick Dinelle, Margaret Dodgson, Faye Goranson, Kathryn Harrod, Helen Horlings, Mary Jane Hradowy, Evalyn Hrybko, Lynda Nash, Carol Oss, and Lorraine Swanson.

We are appreciative of the personal commitment each of you as volunteers make investing your time in support of the organization's mission in your local area, helping to ensure that the ANAC community is a supportive and caring network.

I would be remiss not to mention Marlon Hugh for his efforts on the website and Lyna Newman, President, Americo Meneguzzi, Vice President, Rex Banks, Vice President and Jennifer Fitzpatrick, Nick Kucharew, Cora Hennel-Greer, John Lalley and Jennifer Wong who are sharing their time and expertise as directors of the organization. They are committed with your assistance to provide leadership and support to enable us to deliver more resources in 2016.

Together we can make a difference!

#### **ANAC**

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Facebook: Acoustic Neuroma  
Association of Canada-ANAC

Twitter: @CanadaAN

#### **ANAC Board of Directors**

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John Lalley	Director
Jennifer Wong	Director

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)