

the CONNECTION

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Note From the Editor

I am interested in knowing what kind of medical articles you, the reader, would like to see in the upcoming issues of the Connection. Please email your requests to anac@compusmart.ab.ca or call 1-800-561-2622. Thank-you.

Mona

Acoustic Neuroma and Neurofibromatosis

What is an Acoustic Neuroma?

An acoustic neuroma is a benign tumor that may develop on the hearing and balance nerves near the inner ear. The tumor results from an overproduction of Schwann cells - small sheet-like cells that normally wrap around nerve fibers like onion skin and help support the nerves. When growth is abnormally excessive, Schwann cells bunch together, pressing against the hearing and balance nerves, often causing gradual hearing loss, tinnitus or ringing in the ears, and dizziness. If the tumor becomes large, it can interfere with the facial nerve, causing partial paralysis, and eventually press against nearby brain structures, becoming life threatening.

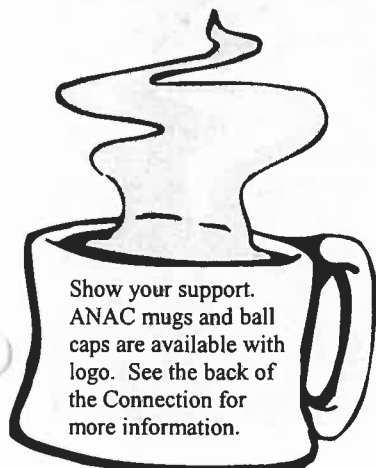
How is an Acoustic Neuroma diagnosed?

Early diagnosis of an acoustic neuroma is key to preventing its serious consequences. Unfortunately, early detection of the tumor is sometimes difficult because the symptoms may be subtle and may not appear in the beginning stages of growth. Also, hearing loss, dizziness, and tinnitus are common symptoms of many middle and inner ear problems. Therefore, once the symptoms appear, a thorough ear examination and hearing test are essential for proper diagnosis. Computerized tomography (CT) scans and magnetic resonance imaging (MRI) are helpful in determining the location and size of a tumor and also in planning its microsurgical removal.

How is an Acoustic Neuroma treated?

If an acoustic neuroma is surgically removed when it is still very small, hearing may be

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more information.

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preserved and accompanying symptoms may go away. As the tumor grows larger, surgical removal is often more complicated because the tumor may become firmly attached to the nerves that control facial movement, hearing, and balance.

The removal of tumors attached to hearing, balance, or facial nerves can make the patient's symptoms worse because sections of these nerves must also be removed with the tumor. As an alternative to conventional surgical techniques, radiosurgery may be used to reduce the size or limit the growth of the tumor. Radiosurgery, utilizing carefully focused radiation, is sometimes performed on the elderly, on patients with tumors on both hearing nerves, or on patients with a tumor growing on the nerve of their only hearing ear. If the tumor is not removed, MRI is used to carefully monitor its growth.

What are the two types of Acoustic Neuroma?

There are two types of acoustic neuroma: unilateral and bilateral. Unilateral acoustic neuromas affect only one ear. They account for approximately 8 percent of all tumors inside the skull. Symptoms may

develop at any age but usually occur between the ages of 30 and 60 years.

Bilateral acoustic neuromas, which affect both ears, are hereditary. Inherited from one's parents, this tumor results from a genetic disorder known as neurofibromatosis-2 (NF2). Affected individuals have a 50 percent chance of passing this disorder on to their children. Unlike those with a unilateral acoustic neuroma, individuals with NF2 usually develop symptoms in their teens or early adulthood. Because NF2 patients usually have multiple tumors, the surgical procedure is more complicated than the removal of a unilateral acoustic neuroma. Further research is needed to determine the best approach in these circumstances.

In addition to tumors arising from the hearing and balance nerves, NF2 patients may develop tumors on other cranial nerves associated with swallowing, speech, eye and facial movement, and facial sensation. NF2 patients may also develop tumors within the spinal cord and on the brain's thin covering.

Scientists believe that both types of acoustic neuroma form following a loss of the function of a gene on chromosome 22. A gene is a small

section of DNA responsible for a particular trait like hair color or skin tone. Scientists believe that this particular gene on chromosome 22 suppresses the growth of Schwann cells. When this gene malfunctions, Schwann cells can grow out of control. Scientists also think that this gene may help suppress other types of tumor growth. In NF2 patients, the faulty gene on chromo-

some 22 is inherited. For individuals with unilateral acoustic neuroma, however, some scientists hypothesize that this gene somehow loses its ability to function properly as a result of environmental factors

(Editor's Note: This article was reprinted from the National Institute on Deafness and Other Communication Disorders fact sheet.)

Inspirational

Friends are flowers that
never fade.

The secret of achievement is to not let what
you are doing get to you
before you get to it.

The mighty oak was
once a little nut that
stood its ground.

There is a name for people who are not excited
about their work - unemployed.

A person's true character
is revealed by what he
does when no one is
watching.

Your companions are
like the buttons on an
elevator. They will either
take you up or they
will take you down.

Many a good person has
failed because he or she

had their wishbone
where their backbone
should have been.

If at first you do not succeed,
try reading the instructions.

It is better to be silent
and be considered a fool
than to speak and remove all doubt.

The grass may look
greener on the other
side, but it still has to be
mowed.

You can win more
friends with your ears
(even one) than with
your mouth.

A minute of thought is
worth more than an hour
of talk.

The art of being a good
guest is knowing when
to leave.

President's Corner

I am proud to inform you that your Board of Directors has and continues to contribute positively towards our future successes, to stimulate the positive development of our organization. However, it is my conviction that more than an active BOARD is necessary if an organization is to function effectively and efficiently. Another essential element must be evident. The meaningful involvement of individuals and participation of individuals within the organization must be encouraged and appreciated.

To focus briefly upon meaningful involvement, please allow me to bring these three items to your attention: a) Chapters, b) Membership, and c) the Medical Advisory Board (MAB)

a) CHAPTERS: On Saturday, Feb. 17/01, Carol, my wife, and I accepted the warm invitation to attend a Chapter meeting in Kitchener, Ont. The meeting was friendly, casual and extremely informative. All of us were engaged in the most essential and vital component of any successful organization. TALKING TO ONE ANOTHER! The entire afternoon kindled within me a desire to attempt to express the warmth and sincere concerns to others. I urge all members to attend your Chapter meetings, or to form one, if it doesn't exist in your area, and to communicate your concerns and needs to the undersigned. Your INVOLVEMENT is essential for the positive growth of our organization. Trenny Canning and Doug Specht, I thank you for the invita-

tion and thank you for helping me to become more aware of the needs of our members.

b) MEMBERSHIP: On July, 1985, our membership totaled 191.....and today we have 391 members..... A reminder to those who have not yet renewed: Please forward your renewal to our Association Head Office (P.S. our Treasurer and Secretary shall be contacting you to encourage your 'RENEWAL')

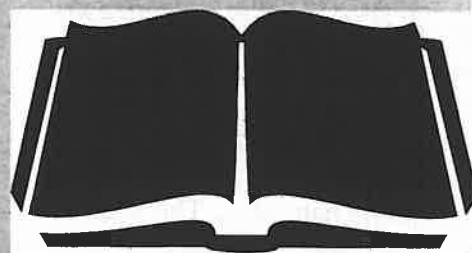
c) MEDICAL ADVISORY BOARD (MAB) - During the November 2000 meeting of the Board, I received and accepted eagerly the following mandate. STRATEGY: "To promote efficient, effective, and collaborative relationships with the Medical Advisory Board (MAB)". To initiate my involvement with the MAB, a personal letter was forwarded to them before Christmas. Another was sent to them in the New Year. Some responses from the MAB have been received. I welcome and appreciate them but I shall appreciate more. Since effective two way communication cannot be left to chance. I am encouraging the MAB to assist us by responding. I also wish to inform all that I shall initiate other tactics of communication with them.

The members that I have been able to meet encourage me to seek the advice of ALL MEDICAL MEMBERS. All ANAC members want to convey their concerns to the MAB, and in many situations, yearn to listen to the professional opinions of the

MAB prior to their enactment of a serious decision.

Yours truly,

Dr. John Oss.,
ANAC President



Welcome New Board Members

ANAC Board Treasurer

The Association is pleased to announce that Carol Oss has joined the ANAC Board as Treasurer. Carol has worked for many years marketing fund raising products to schools, municipal groups, and associations in Quebec and Nova Scotia. Since 1980, she has been involved in Estate Planning, Mutual Funds, and Disability and Life Insurance plans with Sun Life of Canada, Aetna, and Equinox.

Carol and her husband, John, are dedicated supporters of ANAC. Their son, Lindsey Sean is a NF2 patient. As mother of four adult children and grandmother of three grandsons and one granddaughter, Carol still finds time and energy to be a volunteer.

Welcome, Carol.

(continued on page 4)

HAPPENINGS!

Nova Scotia Halifax

Contact Person:
Ed Morrissey
1-902- 434-1673
ed.morrissey@ns.sympatico.ca

An active group here, meets every month together with the late deafened adult group, often have speakers, social gatherings, too.

Manitoba Winnipeg

Contact Person:
Leslie Sutherland

In January we had a speaker from the Manitoba Brain Injury Association. It was interesting to learn that those of us who have had a brain tumor have similar difficulties as people who have had an aneurism, stroke, or head trauma injuries. The MBIA welcomes anyone who is interested to the meetings. Next ones are planned for April 3, May 15, and June 26.

Contact Rochelle Ashcroft at
1-203-787-1090

Saskatchewan Saskatoon

Contact Person:
Marion Harvey
1-306-668-6127

Last November, some AN people attended the "Listen-Up Saskatoon Support Group." It was an

enjoyable and practical time. A video and teaching manual on the art of speech reading was presented. Some AN people were able to share their stories and to answer questions. As a follow-up, two AN people took part in a one hour radio show regarding the hearing impaired. It was a great opportunity to tell others of the symptoms, surgical procedures, and recovery experiences of AN!

British Columbia Vancouver

Contact Person:
Naome Soleil
1-604-324-1456

The AN meeting is Saturday, March 17th, 1-3 pm, at the B. C. Cancer Agency. A panel discussion is planned with three AN patients to share their stories of different treatment options, possible complications, recovery, and "getting on with life."

Vancouver Island - Nanaimo

Contact Person:
Evalyn Hrybko
1-250-282-3269

Next AN meeting is Saturday, April 21st, at the Howard Johnson Harbourside Hotel, 12:30-3:00. Guest speaker will be Janet Holland on the topic of lip and speech reading.

Ontario Kitchener/Waterloo

Contact Person:
Doug Specht
1-519-886-4436,
dspecht@golden.net

On Saturday, February 17th, a potluck lunch was held at the home of Trenny Canning, with about 20 people in attendance, including John and Carol Oss. A great time of visiting for all in attendance.

Hugs

It is wondrous what a hug can do. A hug can cheer you when you are blue.

A hug can say, "I love you so", or, "Oh I hate to see you go".

A hug is a "Welcome back again". A hug can soothe a small child's pain and bring the rainbow after the rain.

The hug! There is just no doubt about it.

A hug delights, warms, and charms, it must be why God gave us arms.

Hugs are great for fathers and mothers, sweet for sisters, even fine for brothers.

Chances are favourite uncles and aunts will love them more than potted plants.

Hugs can break the language barrier. No need to fret about the store of them.

The more you give, the more you get of them.

So stretch those arms without delay and give someone a hug today!

Author Unknown



Dear Mailbag,

I had an acoustic neuroma removed over four years ago and I had the total loss of the functioning of one ear and the total loss of the facial nerve on that side. There has been no regeneration. I have had a facial reconstruction and two follow-up procedures and now my face looks very close to normal. My speech is clear. Having lost the input from one ear for balance, when you then also lose some of the input from the eyes it definitely causes problems.

As I live in snow country in Montreal, Canada, I experience a lot of problems with fresh clean sparkling snow. I think the reflection off the snow gives an increase of input from the eyes and I am not able to close my eye to control this input. Another time when I have similar difficulty is in the dark of the night. I had someone install a motion detector light beside where I park my car behind my house because when I drove in at night and climbed out of my

car in the total darkness I found myself almost motionless. I found when I lost all input from the eyes I was not able to send any impulses to the muscles of my legs to pick up one leg after the other and let me walk. I had them set the light to remain on for only two minutes and it is a godsend. My neighbours have gotten used to it and accept it but I have not been able to train my three cats to take a different route to the door so that they do not cause the light to turn on. C'est la vie!

Has anyone else experienced problems with fresh snow?

Eleanore Van Norman
Email: vnorman@aei.ca

Dear Mailbag,

I had my first operation in August of 1999 to remove a large tumor, which left me with facial paralysis. I had my second operation on June 1st of 2000. This last operation included a tarsorrhaphy, a sling to the lower eyelid, a hypoglossal nerve transfer plus a cross-facial nerve graft. I am facing another operation to take a muscle out of my leg and put it in my cheek to give me a smile. I'd appreciate hearing from other AN patients who have been through similar experiences.

Noreen Keens
Email: noreenkeens@hotmail.com

Dear Mailbag,

I found out I have Acoustic Neuroma July 1997. First, I went to Vancouver Cancer Clinic, they say they have a new machine (stereotactic), the machine is new they need time to prepare. They say 20 to 25 treatments, Monday to Friday. I ask about Gamma Knife but they say because I have some hearing in my ear that it's not good for my hearing.

Then I came a second time to understand what they would do for me. Now, they say they are so busy (the demand on the new machine is so great) they can only give me one dose in one treatment. They said the machine is so new they could not give any long or short-term results of the effect of the treatment. I would have been the second person in Vancouver to receive treatment. They suggested I go to Toronto for treatment because they had more experience. I did not want to go to Toronto because I would have to go by myself, far away, and the weather was too cold for me. I was also afraid of receiving just one treatment because the dose would be so heavy.

So, I then decided to go to Seattle and investigate about the Gamma Knife treatment. They showed me records of results of treatment, the machine, and explained payment and procedures.

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THE NEED

For those dealing with acoustic Neuroma, and their families, information and support are needed. These people rely on the Acoustic Neuroma Association of Canada (ANAC).

We rely on the generosity of our members and other supporters in order to provide this help. Membership fees alone, valuable as they are, cannot finance the organization, so we still need donations from individuals like you.

YOUR GIFT (Charitable Registration # 11877-7168)

Be assured that any gift will be useful to the fullest. You will have the thanks of all people associated with the Acoustic Neuroma Association of Canada, and you will be recognized as a donor in *the Connection*. Revenue Canada also recognizes your gift as a tax-deductible charitable donation.

Should you wish to make a donation, please fill in the appropriate details on the other side of this page.

Your donation will be used where it is needed most. Some possibilities are:

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2. toll-free patient support telephone line
3. the ANAC website
4. publication and distribution of printed materials
5. public awareness and promotion
6. development of local chapters / support groups

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