

the
CONNECTION

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**Acoustic Neuroma
Association of Canada**

**Association pour les
Neurinomes acoustiques
du Canada**

An important aspect of the Acoustic Neuroma Association of Canada's mission is the dissemination of information. The Association does not promote any treatment method over another. That decision is to be made by the individual requiring treatment and their doctor.

Articles on any treatment method published in any issue of the Connection are for educational purpose only and do not represent the views of the Association.

Your comments, ideas, suggestions and financial support are needed and welcomed, and should be directed to:

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Peggy Jumps In

**by Peggy Bray, ANAC
Past President**

I discovered ANAC in 1990 when I returned from Scotland, where I had been living for several years following my AN surgery. I was curious about the Cross Hearing Aid and although the hearing aid didn't work particularly well for me, the specialist gave me something even better: a copy of *the Connection* newsletter and details of an upcoming ANAC meeting in North Vancouver.

I attended my first meeting and jumped into the deep end, agreeing then and there to take over the leadership of the Vancouver Chapter from Tom Walton rather than see the Chapter go under. The group was then meeting in a church basement. We got to know and to learn from each other and from the wide variety of medical experts who came to speak to us.

I initiated a Steering Committee to share the work involved in holding meetings and raising awareness of acoustic neuroma. Committee members sent ANAC information packages to medical professionals, prepared press releases for local newspapers and arranged to have AN symptoms advertised on Lucerne milk cartons. We even managed to get on the airwaves when Evalyn Hrybko's eldest daughter Susanne interviewed me for a program on Vancouver's Co-op Radio.

In 1995, I stepped down as head of the Vancouver Chapter and went to work as Past President. Our big issue at that time was the decision by Health Canada to withdraw financial support from ANAC, a move that affected the Association at all levels. Of necessity we turned our attention to fundraising—at all levels.

Our greatest success locally was literally a "gamble;" we worked at charity casinos. These paid off well enough that we were able to support the 1996 Symposium "From the Patient's Point of View," videotape the main sessions and provide a transcription for our NF2 members who were not able to hear at all.

Proud to recognize the many significant contributions volunteers make in our community... **A Year for Everyone**



Peggy Jumps In, *continued*

I became a member of the National Board of Directors in early 1997. When Shirley Entis resigned to move to Florida and the Association needed a President I agreed to fill the post. It was a case of jumping into the deep end all over again.

By this time ANAC had weathered its financial crisis by relying on the time, energy and contributions made by many members. Even more was required, so belts were tightened, priorities reassessed and volunteers went to work when hours for the National office staff had to be reduced. I kept things going and encouraged membership involvement as we made major changes to the Association's infrastructure. These included adopting many of the recommendations made by the professional Fund Development Study, developing alliances with other medical organizations so we could present a stronger voice to government, and working through the changes in administration and organization that began when Linda Gray, founding member and General Manager *extrodinaire*, retired.

In the fall of 2000, I left the presidency in the very capable hands of Dr. John Oss and again became a Past President. Currently I act as a resource to the President and Board of Directors by providing background that, I hope, contributes to effective steering of the ship, as it were. Along with that, I'm working on the Chapter Development Handbook.

My volunteer involvement with ANAC has given me opportunities to meet new people, connect with others sharing the same concerns and develop abilities within myself. It's been challenging and hectic and wonderful. Like learning to swim in the deep end.

"This open, supportive style of sharing, giving and receiving has developed a wonderful network of members, medical professionals and inquirers. It is the pearl in the oyster; an oasis supplying much needed relief in an information desert."



Health Canada Supports ANAC

This year's application for funding from Health Canada fits nicely with last year's planning conference. Initiatives identified were: increased membership support, increased support from the medical community, and increased public awareness of the services of the association. These objectives were to be addressed through initiatives geared to significantly improve joint and collaborative undertakings with all our stakeholder groups.

ANAC recognized that the lion's share of the proposed activities lay beyond the ongoing resources of the association. Completion of these initiatives would significantly improve our stability as an organization, and our ability to provide leadership and support at a national level. Further, we are fully confident that our efforts at increasing joint and collaborative relationships leading to increase community capacity will lead directly to improved services, reduced duplication, and improved patient and peer support. Finally we believe completion of these initiatives will increase our focus and effectiveness to meet new and emerging challenges and allow ANAC to operate at the leading edge of service provisions to our membership and the affected health community.

In April, 2001, we were notified by Health Canada for their continued support of ANAC over the years. This grant, coupled with our own fundraising campaign, will provide the financial means to sustain the ongoing work of ANAC over the next year.

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(Donations made between March 1 - June 15, 2001)



President's Address

by Dr. John Oss

Actor Robin Williams used the Latin expression, "Carpe Diem – Seize the Day" in the movie, *Dead Poet's Society*.

The expression, *Carpe Diem*, conveys to me a positive and satisfying feeling, a sense of enjoying the daily opportunities of life. In this issue of *the Connection*, may I share with you a few of the positive opportunities that I have had as your 'rookie' President.

On May 9-10, 2001, as your representative, I attended a conference organized by the Canadian Alliance of Brain Tumour Organizations (CABTO) arranged by Fred Smith and Kathleen Ellis. Most conferences provide participants opportunities for growth and this one had a positive impact on me. The participants, including people who were recovering from brain tumours and two prominent Canadian neurosurgeons, were eager to share their feelings and concerns with all. The major activity entailed preparation for a face-to-face meeting with selected Members of Parliament. I gained a greater understanding of an approach to achieve greater public awareness of ANAC's mandate (see side bar).

I share with you the beginning of a letter that I forwarded to our Medical Advisory Board (M.A.B.). "To promote an efficient, effective and collaborative relationships with the M.A.B. is still the challenging endeavor of this President". To 'Carpe Diem', I have attempted to arrange a face-to-face meeting with the M.A.B. who may be attending the Canadian Congress of Neurological Sciences in Halifax (June 2001). However, prior commitments may prevent some physicians from attending this Congress. I'll make you aware of the progress of this venture. If few attend, I shall be arranging a conference call with the M.A.B. at the end of June 2001.

With the competent and professional assistance of Quandary Solutions' staff Cheryl Bauer, Jon Hall and Don Lavers, I am most pleased that once again we "Carpe Diem" and received financial assistance from Health Canada to the amount of \$50,000 for special activities. On April 24, 2001 a letter of appreciation was forwarded to Mr. Karl Benne, Senior Consultant.

Junk Mail or Pertinent Mail As President, I do receive an abundance of mail. At times, it is somewhat difficult to grasp the significance of the information because it may require a very specific training or background. Odin Medical Technologies has forwarded me an extensive amount of literature that has fascinated me and encourages me to request comments from our Medical Advisory Board. (Look for specific articles, in the next issue of *the Connection*.)

Have a pleasant summer, & do try to "CARPE DIEM"

Members of the Canadian Alliance of Brain Tumor Organizations (CABTO) will meet individually with 20 selected MPs to solicit their advice and assistance in meeting the organizations mandate.

Focus #1: Raise awareness of brain and spinal cord tumour issues.

Canadians need to be more aware of brain tumours and spinal cord tumours – their signs, symptoms and long and short-term effects. The available information would address both malignant tumours and the benign tumours, which often cause much longer periods of side effects and disabilities.

Focus #2: Advocate for better tumour statistics.

Canadians deserve better statistical information in regards to all types of brain & spinal tumours at the time of diagnosis (whether malignant, benign, primary or secondary). We require these accurate numbers to obtain necessary and appropriate funding.

Focus #3: Increase funding for research.

Increased funding will lay a firm foundation for research that will bring about a better understanding of the disease. This research would make possible the development of novel treatments, which will lead to a cure and ultimately, the prevention of brain tumours.

Focus #4: An invitation to visit a research centre.

CABTO is willing to arrange a visit for MPs to any one of the many research centres across Canada to learn more about the needs of the research community.



History of the Acoustic Neuroma Association of Canada By Linda Gray

"The vision was (for) an organization of national scope with a distinguished medical advisory board. The mission was to decrease diagnostic time and improve treatment. The focus was simple and succinct: give others what had not been available for them - relieve the pain, anxiety, and the tumultuous search for answers and information."

Editor's Note: This information is a testimony to all the volunteer work that makes the association, both past and present tick and as a way to honour the Year 2001 as the International Year of Volunteers. This information will be available in Chapter Development Handbook, currently under development.

In early 1983 Virginia Garossino, Velma Campbell and Linda Gray met for the first time. The three Edmonton women had had acoustic neuroma surgery within a year of each other, and had encountered individual sets of difficulties and recoveries. They discovered early in their search that there was not a support or information system in place for this unique tumour. Along with husbands Dick Garossino and George Campbell, the group of five agreed to establish a charitable organization to meet those needs and allow others across the country to share experiences and information.

The vision was an organization of national scope with a distinguished medical advisory board. The mission was to decrease diagnostic time and improve treatment. The focus was simple and succinct: give others what had not been available for them - relieve the pain, anxiety, and the tumultuous search for answers and information. The founders realized that success would be totally dependent on enthusiastic, knowledgeable voluntary work from people dealing with Acoustic Neuroma, and their families or health professionals. In March 1984 their dream was realized with the incorporation of the Acoustic Neuroma Association of Canada, a national charitable organization with the vision statement, "The Hope is Recognition and Treatment".

Developing ANAC was a zealous and healing quest requiring much hard work, time and effort to become reality. For many years the work and responsibilities

changed schedules, amount of personal free time, and ultimately their lives. The team divided the responsibilities for greatest effect: Linda, the patient contact and office coordinator; Velma, in charge of Public Relations; and Virginia, the spokesperson and implementer. When the Campbells and Garossinos traveled across Canada no opportunity was lost to promote ANAC and recruit volunteers and supporters. Many committed friends, family members, and professional colleagues became dedicated members throughout the country. The Association grew from these humble beginnings to 'cross Canada' representation with 492 members by the year 2001.

Financed totally for the first two years by the founders and several corporate contributors. The Association received its first grant from Health Canada in 1987 and, along with memberships, donations and gifts in kind, the dream came true. It is due in large part to Health Canada's continued support of the work of ANAC that the Association is able to continue today.

Some of the many activities that have helped the growth of the organization:

- ❖ Information symposiums,
- ❖ participation with our members in research projects,
- ❖ representation at medical conferences,
- ❖ lobbying for payment of out-of-country gamma knife treatments,
- ❖ speaking engagements including classes of University students and seminars in hospitals,
- ❖ press and TV interviews,
- ❖ open-line show guest spots,
- ❖ many newspaper articles including the Canadian Medical Association Journal,
- ❖ workshops for volunteers

Through ANAC's public awareness campaigns this condition has become better recognized and treated. Which is now allowing for a better quality of life after treatment. This is largely due to the help of our Medical Advisory Board, especially its Founding Chair, Dr. Charles Tator, and other dedicated medical professionals.

History of the ANAC, *continued*

Four key accomplishments are:

- ✓ Circulation of ANAC's newsletter *the Connection*, which provides the membership a link throughout the year.
- ✓ Establishment of Facial Neuromuscular Retraining Clinics in Canada based on pioneering methods of Dr. R. Balliet.
- ✓ Production of an information video focusing on hope.
- ✓ Support network for newly diagnosed patients.
- ✓ Heightened awareness of acoustic neuroma in Family Practice level of medicine.

The original vision would not have become a reality without the energy and ideas of people who shared the dream and helped make it happen. To the many, who have worked so hard and to those who take up the challenge in the future, the founders pay heartfelt thanks and a debt of gratitude. We are so proud of what is being accomplished by ANAC members.



Linda Gray, Velma Campbell, George Campbell, Virginia Garossino & Dick Garossino. *From left to right:*

ANAC's purpose is as important today as it was in 1983. The success is the continuing belief from a dedicated membership that the need is still relevant, and that the volunteered time, information and support gives hope, education and friendship to others searching for it. This open, supportive style of sharing, giving and receiving has developed a wonderful network of members, medical professionals and inquirers. It is the pearl in the oyster; an oasis supplying much needed relief in an information desert.

With gratitude and thanks,
From ANAC's founders:

Virginia & Dick Garossino, Velma Campbell, and Linda Gray. George Campbell (now deceased).

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(Donations made between March 1 - June 15, 2001)

A Year for Everyone

2001 IS THE INTERNATIONAL YEAR OF VOLUNTEERS



The Vestibular System Explained

By Jennifer Toland, BScPT, FCAMT, MCPA

What is the vestibular system?

The vestibular system is a group of structures located inside your inner ear and is one of the systems of the body that we use to 'feel'. Unlike skin, which feels hot and cold or rough and smooth, the vestibular system feels movement of your head or whole body and it 'feels' gravity. In other words, the inner ear tells the brain what direction the head or body moves and how quickly, but, also tells the brain if the person is sitting still and if they are sitting up straight or leaning to one side.

The vestibular system is made up of several structures; three *semi-circular canals*, the opening to the canals which are called *otoliths*, the *vestibular nerve* and the areas of the brain that process the information. The semi-circular canals and the otoliths are the 'feelers' that sense the movement or gravity's pull. The nerve sends the information to the brain, which 'reads' it and makes decisions about any action that needs to happen. For example, if someone is falling forwards, that movement and the pulls of gravity are 'picked' up by the semi-circular canals and the otoliths. They send the information through the vestibular nerve to the brain and the brain decides to move the person's feet or body so that they regain their balance and don't fall.

What does the vestibular system do?

The information from the ears is sent to the brain and the brain makes decisions based on what it is 'told'. The brain uses the information for control of balance and posture. There is also a reflex between the ears and eyes (called the *vestibulo-ocular reflex*), which helps to keep one's eyes focused on an object even if their body is moving. The vestibular information is used to move the eyes in an equal but opposite direction to the head movement and therefore the eyes stay relatively still. For example, if you turn your head to the right as you are looking at the computer screen, your eyes move an equal amount to the left. Since your eyes do not just move with your head, you are still looking forward (this works like the dolls with eyes that move so that when you tip their head down, the eyes roll up or you tip the head up and the eyes roll down). This gives you 'gaze stabilization'. If this is not working well, you would 'see' every movement of our head and body. People having problems with gaze stabilization often say that "everything is jittering when I walk" or "everything is moving and I can't see someone's face unless I stop on the sidewalk to see who it is" because they 'see' every movement their body makes when walking. This 'seeing jittering' or movement is called *oscillopsia* and is usually a problem when someone has had an injury to both inner ears (not just one side).

B.A.D.D.

Balance and Dizziness Disorder Society

This new organization is just two years old and rapidly growing in membership. BADD provides support and information for people with vestibular & vertigo problems. They produce an excellent newsletter and meet every other month at St. Paul's Hospital in Vancouver, B.C.

Balance & Dizziness Disorder Society

#314 2121 W.6th Avenue
Vancouver, BC V6K 1V5

badd@vcn.bc.ca

(Note: Yearly membership costs are \$10 and can be sent to BADD c/o 2781 Pt. Grey Road, Vancouver, BC V6K 1A4)

Hints for Dealing with Hearing Loss:

1. Minimize background noise, whenever possible.
2. Reduce distance between yourself and the person you are talking with, as much as possible.
3. It is important to look right at the person's face when talking to them, and keep your hands away from your face, while talking.
4. Good lighting is a must, whenever possible with no glare into the sunlight or shadows.

Notes taken by Evalyn Hrybko from a session on hearing loss presented by Janet Holland at a meeting in Nanaimo on April 26, 2001.

Vestibular System explained ... *continued.*

What types of injuries or diseases affect the vestibular system?

Problems with the vestibular system can be caused by tumours (like Acoustic Neuromas), some types of surgery and infection, shingles, aging,) a blow to the head or diseases of the inner ear (like Meniere's Disease or Benign Paroxysmal Positional Vertigo). Occasionally the problem arises from use of certain medications. Either or both ears may be involved and patients have different symptoms depending on their type of injury and whether it affects one or both ears.

Why do we get dizziness?

Dizziness is the second most common complaint to family doctors (after back pain) and it is estimated 40 – 50 % of people seen by Ear, Nose and Throat Physician's for dizziness had an inner ear problem.¹

The vestibular system picks up all the information about how we move and what position we are in and sends it to the brain constantly. The brain is expecting to get matching information from each ear (the information is usually equal but opposite from each ear). When something happens to change the information from the ears so that it no longer matches, people start to have problems like dizziness and poor balance. These types of changes may be; getting information from one ear only (like after some surgeries), or getting only a slow, quiet signal from one ear and a normal signal from the other. The brain is only able to read the type of information that it expects to get and therefore is 'confused' by changes or when it does not match up.

What is Vestibular Rehabilitation?

Vestibular Rehabilitation is a series of exercises given to the patients to try to teach the brain to 'read the changed information' after an injury. For example, if the vestibular nerve is cut during surgery, the brain is now only getting information from one ear. It has to learn that this is now 'normal' and to be able to read that information and make decisions based on it. **Habituation exercises** refer to the exercises, which repeat the movements that cause dizziness in order to reduce the symptoms of dizziness. They are designed so that the brain can practice reading information that usually causes dizziness for the patient. Once the brain recognizes that this is the new 'normal' information, the dizziness will stop.

Balance exercises are used to allow the body to practice using the vestibular information to make decisions and be able to stay balanced in

Annual General Meeting

The next AGM is planned for August 17-19 in Waterloo. Watch for details in the next issue of *the Connections*, or contact the National Office at 1-800-561-2622

News Release:

Polestar N-10, For Intraoperative M.R. Imaging – Sets a New Standard in Neurosurgery.

Polestar N-10 has been cleared by the U.S. Food & Drug Administration and is the world's first compact MR image guidance system designed for use in a standard operating room.

Polestar N-10 allows the neurosurgeon to accurately localize the brain tumour, avoid critical structures and visualize the margins of surgical resection in real time. All the while eliminating the uncertainties from brain shift and the changes in the brain throughout the surgery.

Key advantages include:

- ✓ helping to ensure the entire tumour is removed.
- ✓ reducing damage to healthy tissue
- ✓ obtain valuable post-operative information before the patient leaves the operating room.

¹ Nedzelski J, Barber H, McIlmoy L: *Dizziness in a Dizziness Unit*. Journal of Otolaryngol. 15:101-104, 1986

Vestibular System explained ... continued.

challenging circumstances. Balance is not only related to the vestibular information, it is a combination of that information together with what we see and what we feel in our feet and legs. Patients may need exercises to teach them to use all the information available instead of focussing on only one type of information. For example, after a vestibular problem the patients often rely only on vision for balance and need exercises to learn to 'listen to their feet and inner ears' again. Patients may also be given exercises to improve their ability to walk.

Gaze stabilization exercises are used to improve the ability to focus their eyes on the outside world while moving or walking. Often people with gaze problems will have difficulty with reading and other visual related tasks as well. In addition, there are times when eye movements or other visual tasks may produce dizziness and therefore habituation exercises should be used.

All patients at the Vestibular Rehabilitation Program at Sunnybrook and Women's College Health Science Centre are given a walking program. Walking benefits patients in many ways. As patients have difficulty with dizziness and balance they often begin to limit their activities, and as a result they are able to do less and less. Walking gives the patient daily exercise in addition to giving the brain a chance to use what it is learning with the exercises!

One of the biggest parts of vestibular rehabilitation is education. The patient has an opportunity to discuss their particular symptoms and to find out why these strange things are happening. They learn what exercises are best for them and why, and safety issues are discussed in detail.

Vestibular rehabilitation or exercises to improve the symptoms of vestibular disorders began in the 1940's² and have more recently been studied to determine if it is truly effective³⁴⁵⁶⁷⁸⁹. Overall the research

² Herdman SJ. *Advances in the Treatment of Vestibular Disorders*. Physical Therapy. 77(6): 602-618, June 1997

³ Blatt PJ, Georgakakis GA, Herdman SJ, Clendaniel RA, Tusa RJ: *The Effect of the Canalith Repositioning Maneuver on Resolving Postural Instability in Patients with Benign Positional Vertigo*. The American Journal of Otology, 21:356-363, 2000

⁴ Whitney SL, Metzinger Rossi M: *Efficacy of Vestibular Rehabilitation*. Otolaryngologic Clinics of North America, 33:3, pp659-672, 2000

⁵ Strupp M, Arbusow MD, Maag KP, Gall C, Brandt T: *Vestibular exercises improve central vestibulospinal compensation after vestibular neuritis*. Neurology 51: 838-844

⁶ Cowland JL, Wristley DM, Strasnick B, Jacobson JT: *Efficacy of Vestibular Rehabilitation*. Otolaryngol Head & Neck Surgery 118:49-54, 1998

⁷ Keim RJ, Cook M, Martini D: *Balance Rehabilitation Therapy*. Laryngoscope 102: 1302-1307, November 1992

Interesting NF2 Facts:
Submitted by Jonathan Kantor

I read with interest your spring bulletin and wanted to offer some corrections. Firstly, only 50% of NF2 cases are hereditary with the remaining 50% being new mutations. Also to add more clarity to NF2 related problems note that 50% of NF2ers also have one or more spinal lesions. In many cases they never cause problems but they can be very debilitating. 90% of NF2ers have ocular abnormalities, cataracts being very common. These abnormalities may range from insignificant items to tumours.

Make a Donation:

There are various ways and different special occasions that you can use to make a donation to ANAC. Instead of pondering what to buy, make a donation to ANAC.

Donations can also be made in "Memory of" someone special. ANAC will send a special card to the person you specify.

It is easy to make a donation, just contact the national office, phone 1-800-561-2622.

⁸ Cohen H: *Vestibular Rehabilitation Reduces Functional Disability*. Otolaryngol Head & Neck Surgery 107: 638-643, 1992

⁹ Horak FB, Jones-Rycewicz C, Shumway-Cook A: *Effects of Vestibular Rehabilitation on Dizziness and Imbalance*. Otolaryngol Head & Neck Surgery. 106: 175-179, 1992

Vestibular System explained ... *continued.*

shows that most patients show some improvement in balance and dizziness following vestibular rehabilitation, but the best results vary. Some improve a little, some a lot and some have their symptoms go away completely.

One of the biggest factors influencing the amount of benefit from treatment is the type of exercise program. If it is designed specifically for each person, they get more benefit than if everyone gets the same exercises. The people who respond the most to customized exercise programs only have problems with one inner ear, have not have the dizziness or bad balance for a long time and have dizziness that is caused by movement. The people who do not seem to improve much are those who have severe problems in both ears¹⁰ or who have other medical problems (like a stroke or old head injury).

There are some people who do not benefit from vestibular rehabilitation. They may have a vestibular disorder, which does not change with rehabilitation, like Meniere's Disease, or some people may have difficulty improving their symptoms for other reasons (other health problems or difficulty in completing their exercises).

How do I find out more?

Unfortunately, vestibular rehabilitation is not widely available in Canada. It is offered mostly in larger hospitals in large cities like Sunnybrook and Women's College Health Sciences Centre in Toronto, or in some specialized clinics like the Dizziness and Balance Rehabilitation Clinic in British Columbia.

If you have a vestibular disorder or are experiencing some of the problems discussed above, please discuss the possibility of vestibular rehabilitation with your physician.

Written by:

Jennifer Toland, BScPT, FCAMT, MCPA

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USA based Patient Advocate Foundation:

The Patient Advocate Foundation is a non-profit organization that serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys. The Patient Advocate Foundation seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability.

Contact information:

help@patientadvocate.org

Check out their website:

www.patientadvocate.org

President's Request:

I am requesting your assistance to help me prepare for a meeting with the Medical Advisory Board for ANAC. Kindly forward to me via email, letter or telephone) any major concern or request for information. We would like to hear about your experiences with diagnosis and advice provided by your neurosurgeon and / or family physician.

You can contact Dr. John Oss at:

137 Chamonix
Ste. Agathe Sud, QC J8C 2J7

Phone: (819) 324-0293

carol.john.oss@sympatico.ca

¹⁰ Telian SA, Shepard NT, Smith-Wheelock M, Hoberg, M: *Bilateral Vestibular Paresis: Diagnosis and Treatment*. Otolaryngol Head & Neck Surgery. 104:67-71, 1991



A Tribute to Tom Walton

by Evalyn Hrybko

2001 is the International "Year of the Volunteer". As a founding member of the Vancouver AN Chapter, Tom Walton is known as one terrific volunteer. It was about 16 years ago that Tom, his wife, Helen and Maureen Murphy began holding ANAC meetings. The Waltons opened their home and hearts to people. Even inviting out of towners to stay with them. At meetings, Tom had a wonderful way of making everyone feel welcome, like being part of a family.

For many years, Tom wrote letters, kept in contact by phone, and visited patients in hospital. He was instrumental in organizing the 1987 Vancouver Acoustic Neuroma Symposium, which was a great success with over 100 people in attendance. When Tom and Helen returned to England for a visit, they met with acoustic neuroma patients and encouraged them to start chapters there.

The Waltons moved from North Vancouver, B.C. to live in Lac La Hache for a while. They are now enjoying the Gibsons area on the Sunshine Coast. In June, Tom will be celebrating his 80th birthday, so our very best wishes for a wonderful year.



Jane's Story

by Jane Smith

When I tell people that I was beginning to think it was all in my head, their response is often, "And, you were right!"

For many years, I knew something wasn't quite right with my body. I would have episodes of sharp, stabbing pain deep in my ear, yet there was no infection. My constant companion was a high pitched squeal in my left ear and slight hearing loss. I began to notice that balance was becoming a real issue.

After years of talking to doctors and not getting any answers, I got a wake up call. One morning, I tried to get out of bed and ended up on the floor. I picked myself up but kept falling over onto my right side. A local doctor thought I probably had an ear infection and referred me to an ear, nose, and throat specialist. After several months of waiting to get an appointment, I had a hearing test, which showed a slight loss of hearing in both ears, but nothing to be concerned about. However, he ordered a CAT scan without the IVP dye because of a previous allergic reaction. Another six month wait.

Several weeks after the scan, I called the doctor's office for results. There was another wait for an appointment to learn that the test was inconclusive, but the left internal auditory canal was approximately 2mm wider than the right, and an acoustic neuroma could not be ruled out. Because of a history of cardiopulmonary arrest following intravenous contrast administration, it was advised that investigation be done with an MRI. The ear, nose, and throat doctor didn't think that was necessary but agreed to send me to a colleague.

Months later, the second specialist also felt an MRI was unnecessary without a previous history of tumours. "Now wait a minute. No one asked me that question before. Do lumps taken off nerves or a growth out of the arch of my foot qualify as tumours?" With what seemed to be a great deal of reluctance, an MRI was ordered, and I was told that a report would be sent to my family doctor.

It took 11 months to get an MRI. A week later, I received a call from the specialist's office, saying I could either come in the next week or wait a month as the office was closing for holidays. The film showed a

**Jane's Story**

by Jane Smith

brain tumour, probably an acoustic neuroma approximately 2 cm. He told me to go home and educate myself, and he would refer me to a neurosurgeon who should get in touch within a week. It turned out that the neurosurgeon had gone on holidays, the office was closed, and I could expect to hear from the surgeon in six weeks to two months.

I was desperate and not prepared to wait passively any longer. Through contacts, I made an appointment with another neurosurgeon. At last, I was able to talk to someone who understood. Decisions were made for an operation, but it would take 4 months to get an operating room. As the hospital was some distance from home, arrangements were made for me to be in town the day before surgery to have all the required tests for hearing, balance, etc. done.

With suitcases packed and mentally prepared, I was told there were no beds. In fact, surgery was cancelled for various reasons "four times". I called my MLA's office but was not able to talk directly to my elected representative unless I would agree to give the constituency office my medical number and access to my files. I asked that my concerns be passed along to the MLA and if I didn't hear back, I would take my story to the press.

At the same time, I contacted the local MP's office and was told that although a lot of the funding for medicare came from the federal government they were not interested in my problem, and furthermore, no one ever called their office asking questions about how the money the federal government provided was spent by the provincial government.

After my surgeon called to say there would be further delay due to more urgent cases on the waiting list, I made another call to the MLA's office and this time gave them my medical card number. I was informed that the MLA would not be contacting me, but someone in the ministry would call that same day. No one called that day but eventually someone did get back to me.

My doctor and his colleagues at the hospital were doing everything possible to get me in. It was becoming obvious there was something fundamentally wrong with

our medical system. Time to go to the press. Maybe they would give some publicity to the whole issue of unreasonably long waits. One of the local newspapers was interested and wrote an article; one of the provincial papers flew in a photographer, and the article made the front page. Camera crews arrived at my home and interviews were aired three times. The hospital was also contacted and agreed that the situation was as I described.

A transfer to another surgeon, who was less likely to have his surgical time cancelled due to an emergency, resulted in a new date for surgery, and I could see my journey through the labyrinth was coming to an end. At the end of March 1999, I had the acoustic neuroma removed in Vancouver by an excellent surgical team. I learned that hospital staffs are as frustrated with the system as their patients.

Although I had symptoms for many years that no one recognized, the last three and a half years I became determined to find out what was wrong. I now realize that our medical system is no longer the envy of the world. Our system is at best okay, at times arrogant, and sometimes fails to meet people's needs. The decision to go to the newspapers and television stations to air my story was not an easy one, but I hope the public attention brought to the problem of long waiting lists will help other patients.

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My Acoustic Neuroma Story

by Marian Harvey

Marian Harvey, farms near Saskatoon, with her husband Elwood. Her favourite past time is to ride her horse "Snickers". She has three children & nine grandchildren.

It is now two years since my journey through the "Acoustic Neuroma Experience" started for real, and I am finally getting it down on paper to share with you. As each step changed the way I looked or the way I felt, I couldn't quite know what the outcome would be ... always looking ahead to the next treatment or the next appointment.

It all began about four years ago when I became aware of a gradual loss of hearing in my one ear. I thought it was merely a build up of wax. On having the doctor flush it out on two separate appointments, I resigned myself to the knowledge that I was at the age where you might need a hearing aid. (After all, I was sixty at the time!)

Eventually I felt a slight 'fullness' in the ear and then a numbness or tingling sensation on that side of my face. This was more serious and a referral to a specialist, followed by a CT Scan, diagnosed a 'growth' deep in the 8th cranial bone at the end of the auditory nerve, and needing 'the skull base team' at the University Hospital in Edmonton.

In June 1999, Drs. Oldring and Broad removed the tumour. It was a 13 hour surgery and though my head seemed to weigh 200 lbs. and I was completely helpless at first, I experienced no pain. I can't say

enough about the wonderful care I received throughout the ordeal. We are so fortunate to have such talented doctors and so many compassionate nurses and other staff at times like this.

The facial nerves and eye on the right side of my face

"As each step changed the way I looked or the way I felt, I couldn't quite know what the outcome would be ... always looking ahead to the next treatment or the next appointment."

were really affected, but I had hopes of the nerves regenerating in four to six months. I was so thankful that the tumour was benign and the rest I could overcome in time. The gaping eye was the hardest to live with that first summer, as it was so sensitive to the sun and wind.

I also felt extreme fatigue and looking back on it now, I wish I had not tried to be such a hero and fight it so much. I will never know if asking for more help and support in those early months would have made any difference to my recovery or not. However, at the time you compare yourself to those suffering through a terminal illness and feel so lucky that you don't say anything.

By the end of August I had contracted ANAC and received their information booklets. As well I talked with three ANAC contact persons living in Saskatoon. This was a wonderful feeling to at last talk to others who had experienced a neuroma and to hear of their frustrations too.

By the time of my check-up with the doctors in Edmonton in late November 1999, they could tell that my eye had not started to blink, the bottom lid was still gaping, and the tests done by the physiotherapist did not show any sign of the nerves regenerating.

Around this time I attended a meeting in Saskatoon of other Acoustic Neuroma "survivors" and as I looked around the room I tried to guess who were the patients. This gave me renewed hope that I, too, would someday return to normal and be able to smile. I heard about their different experiences, recovery rates, and possible exercises I could do. I wish I had been able to meet with such a group a little earlier in the process.

In January 2000 I was given an EMG, which confirmed what was quite obvious to me that the nerves had no sign of movement. Dr. Keohane then inserted the gold weight in the top eyelid, stitched the corner of my eye and raised the eyebrow. What a relief that was to feel the moisture stay in my eye for a few hours and not need an eye patch just to step outside the door.

Dr. Keohane suggested the next step, which was the connection of the nerves in the tongue to the nerves in the cheek. I wanted to hear from some people who had experienced this and seek some advice before I agreed to it. From a list obtained from ANAC, I wrote to about sixteen patients from all across Canada. They wrote, faxed,

Marian Harvey's Acoustic Neuroma Story ... *continued.*

e-mailed or phoned me right away, telling of their surgeries and the varying results. From this response I was encouraged to have the procedure done, and the sooner the better.

I had another EMG done in Saskatoon before going to Edmonton in April 2000. Dr. Oldring

performed the 'nerve attachment' part and Dr. Keohane did the other work needed, which straightened my mouth more or less. They still advised me to be patient as the nerves heal so slowly and facial retraining exercises are needed to encourage movement.

Last winter I joined "Listen-Up", a support group for hard of hearing and late deafened. I found this to be very helpful in learning speech reading and other ways to cope with my one-sided deafness. They also devoted one meeting to Acoustic Neuroma information, where eight of us were able to share our stories and tell about the disease. Following this, one of the members invited two of us to be on his radio show for the hard of hearing.

... "I attended a meeting in Saskatoon of other Acoustic Neuroma "survivors" ... This gave me renewed hope that I, too, would someday return to normal and be able to smile ... I wish I had been able to meet with such a group a little earlier in the process."

In the fall I was referred to the Adult Speech Therapy Department at City Hospital. I find this most beneficial as the therapist teaches the facial retraining exercises as well as working with my speech. I know I should be spending up to an hour a day on these and practice holding my mouth in the center when I talk.

I still have to use a drinking straw and find that getting my mouth around certain foods is messy. I had an MRI done in November and it showed no signs of any recurring tumours. When I am out in the cold, or when I am tired, I find my face really stiffening up and my mouth going over to the one side. However, at rest and especially first thing in the morning, it does look quite normal.

As I approach my second anniversary I am finally returning to my former activities, gaining more confidence as I take up each one. It has been quite a journey and while I wish I knew then, all that I know now, I am not anxious to repeat these experiences.



#2



#3



Marian ... Forever & Always Smiling

Picture #1: Happier Days!

Picture #2: Before Nerve Transfer

Picture #3: Three Weeks After Transfer

**CABTO News**by Naome Soleil

The Canadian Alliance of Brain Tumor Organizations (CABTO) acts on behalf of brain tumour patients across Canada to raise public awareness and advocate for increased government funding for brain tumour research. As an alliance of eight volunteer organizations CABTO's mission is to enhance the quality of life of brain tumour patients and families.

Recent initiatives by the members include a letter-writing campaign and petitions in support of Bill 184 that has been introduced in the Ontario Legislature. The Bill is a step in the process to declare October as Brain Tumour Awareness Month in Ontario. It is hoped that other provinces will do the same.

On May 2001 members of CABTO met to discuss three main issues:

- Advocacy for increasing funds allocated to brain tumour research;
- Closer monitoring of radiation waitlists, nationally;
- Implementation of a system to record, annually, the total number of patients diagnosed with a brain tumour in Canada.

While statistics for malignancies are maintained, there is no equivalent system set up to keep a record of patients with a benign brain tumour. This represents a significant gap in medical information. Also, AN patients who travel out-of-country for treatment may go un-noticed by medical authorities. It is difficult to convince government officials of the demand for updating our technologies and expanding treatment options when statistics are inaccurate or non-existent.

Another ambitious project for CABTO members has been the to planning and organization of meetings with MP's in Ottawa. (See Dr. John Oss' Presidents Address in this issue for more information.)

As the ANAC Representative to CABTO I encourage ANAC members to be active in your communities about brain tumour awareness. Write you local MP about Bill 184 and start a campaign. For more information on CABTO initiatives, you may contact me at (604) 324-1456.

CABTO operates as a division of the Canadian Brain Tumour Network (CBTNet)

**Mail Bag**

*December, 2000**Subject: My experiences with Acoustic Neuroma*

Member Commentary: *After several months of problems with balance, I was diagnosed with acoustic neuroma at the beginning of December 1999. I saw Dr. Noel, an ENT specialist, and Dr. Cameron, a neurosurgeon in Victoria, BC. Dr. Noel gave me the options of surgery or going to the U.S. for stereotactic radiation, which Dr. Noel said was not available in Canada. At that time I was absolutely determined not to have surgery unless there was definitely no other option and I certainly could not afford the alternative I was offered. After researching the condition on the internet and, thankfully finding ANAC, I discovered that, in fact, the therapy is available at the Vancouver Cancer Clinic and has been for some years. A very kind man in Nanaimo, who had undergone the treatment, emailed me and told of his positive experience. I lost the hearing in my right ear overnight (literally) in January 2000 and to cut a long story short, had the treatment in Vancouver in May 2000. So far I have had one follow-up MRI and there is, apparently, no further growth. I must have MRIs on a six monthly basis for about two years. I found Dr. Toyota, who completed the procedure, Dr. Ma, the oncologist (I think) and the staff in the Vancouver clinic most skilful, empathetic and supportive.*

I decided to wait a while before I checked out a suitable hearing aid, but since the ability to hear on my right side is unlikely to return, and having had several distressing (for me) experiences while in group situations, I have decided to check out the Deaf and Hard of Hearing group in Victoria and surf the net to get as much information as possible. By the way, I was told in late November 1999, that I had the hearing of a twenty one year old – add forty years and you get, roughly, my actual age! Five weeks later that level was cut by 50%.

Sincerely, Joan Pritchard

Mail Bag, continued

December , 2000 Subject: Recently diagnosed with acoustic neuroma, requests for information

Request: I have recently been diagnosed with an 8 mm tumour in my right ear. The first thing that has come to mind is where and how can I find the name of a neurologist who has done a number of these operations, preferably successfully. I'm looking for the one who would be acknowledged as the best in his field. If anyone can help me with this request for assistance, (it) would really be appreciated.

Thank you, Ian Vantreight.

Member Response: I had my operation done at the Montreal Neurological Hospital and I had no side effects at all. The hospital is one of the best I have ever been in and English is the everyday language. Dr. Ronald Pokrupa was my surgeon, phone (514) 398-1942; fax (514) 398-2811; and website: www.mcgill.ca/mni/neurosurgery.html I had been referred to the Kingston General Hospital and they told me that they would drill out the tumour and there was a good chance that I would lose my hearing in the right ear, my balance and probably have part of my face paralysed. Dr. Pokrupa said that they would tease the tumour off. The operation took 7 hours and like I said I had no side effects at all.

Hope this help, Bill Wilkinson

Member Response: Sorry to learn of your diagnosis. The good news is that your lesion is very small and all will agree that the smaller it is, the easier it is to treat. As I have a family history of NF2 (an inherited form of bilateral acoustic neuromas) I and other members of my family have had various forms of treatment. I am not familiar with experienced neurosurgeons in BC but ANAC or your local chapter should be able to help.

Gamma Knife radiosurgery (non-invasive) is definitely one consideration. To the best of my knowledge it is not available in Canada. The most experienced in this field is Dr. Georg Noren at the New England Gamma Knife Center and he can be reached at Gnoren@Lifespan.org He has just installed a new machine which delivers fractionated Gamma Knife radiosurgery over a period of several days with the view to better the chances of hearing preservation. Single dose Gamma has been around for 30 years. Some Provincial Medicare plans pay for this type of treatment.

Fractionated Linear Accelerator is another type of radiosurgery. I am familiar with Dr. Gil Lederman at Staten Island University Hospital and he can be reached at gillederman@siuh.edu Also many are going to Dr. Jeffrey Williams at Johns Hopkins University Hospital and he can be reached at jw@jhu.edu

Linear Accelerator is also available in Toronto. I am not familiar with how experienced they are.

Radiosurgery while being non-invasive does not get rid of the tumour but hopefully arrests its growth and in the best case scenarios shrinks it somewhat. Hearing preservation has better chances in radiosurgery but the tumour remains. Being deaf in one ear for 12 years I can tell you it is no big deal. My 16 year old daughter has just had a 9 mm tumour removed surgically and two weeks post op returned to school (ah! The advantages of youth) ... She did lose her hearing.

Check out <http://anausa.org/guest/guest.htm> and read the many entries in their guest book for a better understanding of the options and peoples' experiences and comments.

Jonathan A. Kantor

**Mail Bag, continued***December, 2000**Subject: Gamma Knife treatment*

Member Commentary: *I cannot understand why there is a dearth of information in the Connection regarding Gamma Knife treatment for acoustic neuroma sufferers. Maybe the physicians diagnose the cause of the symptoms when the neuroma is already too big for this type of treatment. Maybe they are unaware of its existence!*

My husband had a slight problem in 1995 with his hearing in one ear. After a year of various diagnosis, an MRI showed the neuroma - the CAT scan did not. He was offered surgery.

We investigated further, and with the help of Dr. C. Tator at the Toronto Western Hospital, we obtained financing from the Ontario government and drove to Rhode Island Hospital to see Dr. Noren who had my husband's history and a copy of his MRI. He and Dr. Tator both deemed my husband to be a suitable candidate for the procedure.

We spent the night in the hospital accommodation, which is like a hotel. Early next morning my husband was taken to see Dr. Noren, had another MRI and a few hours later, after Dr. Noren and his staff had plotted the directions the Gamma rays would take, his head was guided into a large metal hood. Prior to this he had a metal ring attached by a few screws into his skull to keep his head immobile - not painful - a local anaesthetic was given at each site. There are many tiny holes in the metal hood and the rays are directed intermittently over a period of about 1.25 hours. This includes the time it takes to move the patient into various positions so that the rays are directed onto various locations on the tumour. The head piece was removed and we stayed another night, then my husband drove us all over Rhode Island for a week prior to coming home.

His neuroma is smaller and his hearing has improved slightly. He has no other symptoms.

I understand that Ontario and some other provinces again cover the cost of this treatment, which is available in many of the U.S. states and in Europe too. One must obtain permission from the province prior to the procedure, although some people have paid themselves and had to fight to have reimbursement - some successfully. The cost in 1995 was almost \$27,000 (US). We should all lobby our Ministers of Health for the purchase of Gamma Knife equipment and the staff trained to use it. Dr. Tator has tried for years.

I hope this helps those who could be suitable candidates for this treatment.

Doreen Dabbs R.N.

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LEAVE A LEGACY™ is a community based effort to encourage people from all walks of life to make gifts to not-for-profit and charitable organizations.

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account or other financial investment. Many of these approaches can result in tax savings for your estate.

If you are interested in leaving a legacy, please consider the Acoustic Neuroma Association for your gift. You can get help from local LEAVE A LEGACY™ programs or work with a professional advisor such as a financial or estate planner, lawyer, accountant, or insurance agent. A professional advisor will help you to maximize your tax savings.

Other information can be obtained by visiting the Canadian Association of Gift Planners web site at www.cagp-acpdp.org. If you have no other source of information but would like to leave ANAC a gift (or consider it) contact the ANAC National Office who will try to put you in touch with an appropriate person or organization.

You can make a lasting difference!

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Chapter Happenings Across Canada

Vancouver Chapter

A panel of 4 people representing Microsurgery, Gamma Knife, Linac, and an adult child of an AN person with AN attended a meeting on March 17th. The session was informative, especially during the questions and answer period. A sharing time followed.

Contact: Naome Soleil
(604) 324-1456
rtie@interchg.ubc.ca

Courtenay Chapter

Nancy an audiologist will be speaking at the June 26th meeting.

Contact: Evalyn Hrybko
(250) 282-3269
ehrybko@oberon.ark.com

Victoria Chapter

Contact: Rose Christensen
(250) 598-9693
rose@highlands.bc.ca

Nanaimo Chapter

ON April 21st Janet Holland came and gave a presentation on some of the problems and solutions of living with a loss in hearing. It was an excellent time of sharing and for answering questions. Many people commented that this session was very helpful to them. The next meeting in Nanaimo is planned for September 29th, when a professional will be speaking on psychological adjustments regarding AN symptoms.

Contact: Evalyn Hrybko
(250) 282-3269
ehrybko@oberon.ark.com

Saskatoon Chapter

Contact: Marian Harvey
(306) 668-6127
geharvey@sk.sympatico.ca

Winnipeg Chapter

In our May meeting a nurse from the neurosurgery ward came to be our speaker. She answered many questions, providing us with much needed information. The next meeting is planned for June 26th at 7:00 PM at the Health Science Centre Hospital, 2nd floor general cafeteria. The speaker will be Sharon Marks, a nurse from the Gentle Touch Home Health Care Services.

Contact: Leslie Sutherland
(204) 888-3438
or, Rachelle (social worker)
(204) 787-1090

Kitchener/Waterloo

Contact: Doug Specht
(519) 886-4436
dspecht@golden.net

London Chapter

Contact: Doug Flood
(519) 652-3417
seventyeights@AOL.com

Nova Scotia Chapter

A meeting is planned for June, a blind man will be the speaker.

Contact: Ed Morrissey
(902) 434-1673
ed.morrissey@ns.sympatico.ca

Sincere appreciation of donations received:

Contributions made by Reva Kantor, Al Lerner, Sheila Lerner, Harvey Guttman and Jesse Kantor were made in honour of Lindsay Kantor.

A warm thank you goes to Josephine Voorhoeve for her donation.

Thank Goodness for Volunteers:

"A volunteer is a person who can see what others cannot see; who can feel what most do not feel. Often such gifted persons do not think of themselves as volunteers, but as citizen in the fullest sense: partners in civilization." *George Bush*

"Everybody can be great because anybody can serve. You don't have to have a college degree to serve. You don't have to make your subject and your verb agree to serve. You only need a heart full of grace, a soul generated by love." *Martin Luther King Jr.*


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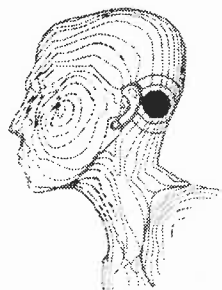
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**Find it! Treat it!
Beat it!**



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 neuromas and other benign tumors 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.



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