the Connection

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http://www.anac.ca

ANAC welcomes you to the launching of its website - check it out!

The Internet is a wonderful vehicle for accessing information and allowing one to keep pace with the latest medical innovations and discoveries. Thanks to the members of the Information Dissemination Committee, ANAC is now 'on-line'. The main ANAC website is accessible to anyone with Internet access and contains information on becoming a member, contacts across Canada, contacts for international associations, common symptoms, treatment options and a 'Frequently Asked Questions' section.

As a bonus to members only, there is a 'Members Only Section' which contains, among other things, past issues of *the Connection*, information on hospital discharge, facial rehabilitation, balance retraining, eye care, headaches, memory and hearing loss, tinnitus, fatigue, etc. Also included in the members only section is a message board, where members can post questions and comments and receive feedback from other members. Feel free to post your thoughts about what you think of our new website on the message board.

Members can access the 'Members' Only Section' through a user name and password, both of which can be found on the mailing label (in brackets) on this issue of *the Connection*. Don't worry if you are not 'on-line'. Information contained on the website will continue to be made available through the National Office and/or *the Connection*.

The website will be updated on a continual basis, so check it out periodically! We are able to track (number of 'hits' only; not specific addresses) the number of people who visit the website so make sure you tell your friends.

Acoustic Neuroma Association of Canada

Association pour les Neurinomes acoustiques du Canada

Your comments, ideas, suggestions and financial support are needed and welcomed, and should be directed to:
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Long-Term Outcomes After Radiosurgery for Acoustic Neuromas

Douglas Kondziolka, L. Dade Lunsford, Mark R. McLaughlin, John C. Flickinger

[*Editor's Note:* The complete article may be found in the *New England Journal of Medicine,* November 12, 1998, Volume 339, pages 1426-1433. Permission to publish this abstract and the accompanying editorial was received from the Massachusetts Medical Society.]

Abstract

Background. Stereotactic radiosurgery is the principal alternative to microsurgical resection for acoustic neuromas (vestibular schwannomas). The goals of radiosurgery are the long-term prevention of tumor growth, maintenance of neurologic function, and prevention of new neurologic deficits. Although acceptable short-term outcomes have been reported, long-term outcomes have not been well documented.

Methods. We evaluated 162 consecutive patients who underwent radiosurgery for acoustic neuromas between 1987 and 1992 by means of serial imaging tests, clinical evaluations, and a survey between 5 and 10 years after the procedure. The average dose of radiation to the tumor margin was 16 Gy, and the mean transverse diameter of the tumor was 22 mm (range, 8 to 39). Resection had been performed previously in 42 patients (26 percent); in 13 patients the tumor represented a recurrence of disease after a previous total resection. Facial function was normal in 76 percent of the patients before radiosurgery, and 20 percent had useful hearing.

Results. The rate of tumor control (with no resection required) was 98 percent. One hundred tumors (62 percent) became smaller, 53 (33 percent) remained unchanged in size, and 9 (6 percent) became slightly larger. Resection was performed in four patients (2 percent) within four years after radiosurgery. Normal facial function was preserved in 79 percent of the patients after five years (House-Brackmann grade 1), and normal trigeminal function was preserved in 73 percent. Fifty-one percent of the patients had no change in hearing ability. No new neurologic deficits appeared more than 28 months after radiosurgery. An outcomes questionnaire was returned by 115 patients (77 percent of the 149 patients still living). Fifty-four of these patients (47 percent) were employed at the time of radiosurgery, and 37 (69 percent) remained so. Radiosurgery was believed to have been successful by all 30 patients who had undergone surgery previously and by 81 (95 percent) of the 85 who had not. Thirty-six of the 115 patients (31 percent) described at least one complication, which resolved in 56 percent of those cases.

Conclusions. Radiosurgery can provide long-term control of acoustic neuromas while preserving neurologic function. (N Engl J Med 1998;339:1426-33.)

Source Information:
From the Departments of Neurological Surgery (D.K., L.D.L., M.R.M., J.C.F.) and Radiation Oncology (D.K., L.D.L., J.C.F.), University of Pittsburgh, Pittsburgh. Address reprint requests to Dr. Kondziolka at the Department of Neurological Surgery, Suite B-400, University of Pittsburgh Medical Center, 200 Lothrop St., Pittsburgh, PA 15213.

Treatment of Acoustic Neuromas

Editorial

Acoustic neuromas (vestibular schwannomas) are benign tumors of the eighth cranial nerve. They are unilateral and typically become symptomatic after the age of 30 years. Bilateral tumors usually are present in type 2 neurofibromatosis, are transmitted in an autosomal dominant fashion, and have a deletion in the long arm of chromosome 22, probably representing inactivation of a tumor-suppressor gene. Acoustic neuromas usually present with tinnitus, a unilateral reduction in hearing, and gait imbalance. If these symptoms are disregarded and the tumor becomes large, it can lead to facial numbness, weakness or twitching, or even signs of brain-stem compression, such as numbness or weakness of the trunk or extremities, difficulty swallowing, or hoarseness. Rarely is the tumor large enough to cause hydrocephalus. Patients often report hearing loss or "stuffiness" in one ear, which may be slowly or, in some cases, rapidly progressive; these symptoms can be mistaken for signs of occlusion of the eustachian tube or otitis media and be treated with antibiotics or decongestants. Persistence or worsening of symptoms usually prompts an audiogram. Asymmetric reduction in hearing or speech discrimination is then evaluated further with magnetic resonance imaging (MRI), which should clearly demonstrate the presence or absence of the acoustic neuroma or other lesion adjacent to the eighth cranial nerve. The tumor results when Schwann cells proliferate within the vestibular portion of the nerve, usually beginning in the internal auditory canal and then extending into the cerebellopontine angle. Occasionally, schwannomas can arise on other cranial nerves, particularly the fifth or seventh. These schwannomas usually grow extremely slowly, over decades.

The first surgical removal of an acoustic neuroma was performed in 1894. Surgical technique has improved dramatically in this century, with the advent of the operating microscope, neuroanesthesia, and intraoperative monitoring. With optimal results, the tumor is removed completely and safely and neurologic function is preserved at the preoperative level, particularly with respect to hearing and facial movement and sensation.

In recent series (reviewed by Sekhar et al. (1)), complete tumor removal was reported in 97 to 99 percent of patients, mortality was below 1 percent, and facial movement was normal or nearly normal in 94 to 97 percent of patients with small tumors and 28 to 57 percent of those with large tumors, as judged one year after surgery (some patients had temporary weakness for weeks or months after the operation). Patients with good hearing and small tumors retain their hearing in 45 to 82 percent of cases. The frequency and severity of the postoperative neurologic deficits increase with increasing tumor size. (1) Because of the morbidity and neurologic injury that can occur with surgery, other treatments have been developed, among them external-beam irradiation and stereotactic radiosurgery. In 1971, using multiple radiation sources and exposure ports, Leksell (2) sought to maximize the irradiation of the tumor and minimize the irradiation of the surrounding tissue. He called his instrument a gamma knife, and the stereotactic technique is now called radiosurgery. Great strides in instrument design, imaging, and computational power now allow the delivery of large doses of radiation to simple or complex targets with relatively low exposure of surrounding structures.

In this issue of the Journal, Kondziolka and colleagues describe their experience with radiosurgical treatment of acoustic neuromas. (3) They report a low frequency of facial weakness or numbness after treatment. The rate (47 percent) at which they were able to maintain hearing levels that were useful before treatment is similar to that reported in some surgical series, and the 61 percent rate of preservation of some degree of hearing is superior to the results in almost all surgical series. Clearly, shorter hospitalization and less morbidity after radiosurgery than after surgical removal make the procedure less burdensome to patients.

However, since radiosurgery does not eliminate the tumor, it is imperative to know how effectively irradiation prevents future growth of the tumor. Kondziolka et al. address this issue by presenting data from patients who were followed for at least five years after radiosurgery. In only 4 of their 162 patients was subsequent tumor growth sufficient to require surgical removal; this recurrence rate is equal to or better than that achieved in many surgical series.

This important study leaves several questions unanswered. The treatment changed during the five years described in the report: more than two thirds of the patients received doses of radiation to the tumor edge that were higher than the 14 Gy that the authors now use in the treatment of acoustic neuromas. In their studies in animals, tumor regression measured three months after irradiation was substantially less when the dose was 10 Gy than when it was 20 or 40 Gy, and there was no reduction in the vascularity of the tumor at the lowest dose. (4) They state in an earlier clinical study that control of tumor growth was maintained with use of their current treatment dose of 14 Gy, (5) although that study separated patients according to the method of treatment planning (computed tomographic imaging or MRI) rather than according to the radiation dose, and the follow-up was shorter than two years for the group receiving the lower dose and MRI-planned treatment.

In the current report, only 97 of 162 patients underwent scanning more than five years after treatment, 20 patients were lost to follow-up, and 32 patients either refused or otherwise failed to undergo late MRI. These 32 patients were doing well clinically, but a good clinical result can be expected even if there is tumor recurrence. In the current report, we cannot determine the duration of the actual radiologic follow-up periods for the 46 patients treated with the 14-Gy dose. Recent studies of acoustic tumors treated without surgery found no growth in 26 to 83 percent of patients over one or two years of follow-up. (6) Thus, some of the tumors in the series of Kondziolka et al. probably would not have grown, even without radiosurgery. Finally, we do not know the radiation dose for the four patients who required surgery to manage tumor growth after radiation.

Therefore, from the current study, we really do not know the success of radiosurgery in controlling these tumors beyond a few years. As the authors have stated, "Because slow-growing tumors such as vestibular schwannomas often take years to progress, any decrease in tumor control from using lower doses could take many years to detect (possibly 5 to 10), while decreased cranial neuropathy rates can be detected with 2 years of follow-up." (5) When tumors recur after radiosurgery, their surgical removal without destruction of the facial or other cranial nerves is substantially more difficult than it is when radiosurgery has not been performed. (7,8,9). Radiosurgery conceivably may even induce malignant transformation of the tumor or cause new tumors, although this complication is apparently rare. Irradiation of Schwann-cell tumors in type 1 neurofibromatosis can lead to malignant transformation. (10) Typically, secondary oncogenesis occurs well after the longest duration of

follow-up in the series reported by Kondziolka et al. External-beam irradiation to the head can induce tumor growth at the base of the skull (11) and triton tumors (malignant tumors with rhabdoid features). (12) For instance, a case report documents the presence and fatal expansion of a triton tumor within an acoustic neuroma five years after radiosurgery. (9) When radiotherapy is considered for a benign, surgically curable tumor in a young patient, this risk of inducing a secondary tumor must be seriously weighed. It will be decades before the incidence of this complication is known. External-beam irradiation can also cause intracranial arterial occlusion, (13) although there are no reports to date of such accelerated atherosclerosis after radiosurgery. The anterior inferior cerebellar artery, which is the primary source of blood supply to the lateral pons and upper medulla, lies right next to the surface of acoustic neuromas.

Gamma-knife and linear-accelerator radiosurgery have provided important new approaches to treatment for some intracranial lesions and ultimately may prove to be valuable in the treatment of acoustic neuromas. Although the report by Kondziolka et al. lays the groundwork for determining the rate of tumor control, the data presented cannot yet define just what this rate is. Surgical removal can be incomplete and does not guarantee protection against recurrence, but in the majority of patients, surgical resection precludes the need for any further treatment. One MRI scan is obtained three years postoperatively to confirm curative resection. After stereotactic irradiation, the tumor remains in situ and must be monitored and imaged periodically for an as yet undetermined number of years (and perhaps decades). Nonetheless, because morbidity is lower and cranial-nerve function is as good after radiosurgery as after surgical removal, it is imperative that studies such as that by Kondziolka et al. continue.

Laurence H. Pitts, M.D.
Robert K. Jackler, M.D.
University of California, San Francisco
San Francisco, CA 94115

June 1999
Dear Members and Friends of ANAC,

Our Annual Fundraising Campaign for 1999 is underway.

ANAC has grown and strengthened through the donations and volunteer energy that each of you has contributed in so many different ways. Together we have created an organization that provides support, information and education to its membership, people who are newly diagnosed with acoustic neuroma and the medical community.

With your continued energy and financial help, ANAC will move successfully into the new millenium. Please respond generously to *The ANAC Annual Fundraising Campaign for 1999.*

Thank you,

Peggy Bray, President,
& Members of the Revenue Generation Working Committee

(l-r) Glyn Smith, Peggy Bray, Linda Gray and Nellie Alger;

A New National Coordinator

Ian McCormack has left ANAC to become the full-time Executive Director of another non-profit organization. This is a career opportunity for him and we wish him well.

Our new national coordinator is Glyn Smith and we're very pleased to have him on board. He's highly qualified, with extensive experience in the medical field, where he's done everything from front-line lab work to senior management, from planning and implementation to writing policy manuals. His background also includes service on the boards of professional and recreational associations, so he is very familiar with association structure from both ends of the spectrum.

We're all looking forward to working with him.

President's Corner

One of the highlights in this issue of *the Connection* is the launching of the ANAC website. Its successful development is the result of commitment and perseverance from a small group of volunteers over the past two years. The site will present information on different issues related to acoustic neuroma and will include personal accounts and articles written by medical specialists. It will be a strong resource for information related to the different treatment options and procedures for acoustic neuroma.

ANAC supports the right of any individual faced with an acoustic neuroma to be informed of, and have access to, all treatment options. The website will augment our new booklet on stereotactic radiosurgery, the updated *ANAC Overview Handbook*, and the various articles that have been published in *the Connection*, including, in this issue, a focus on long-term outcomes after radiosurgery (Gamma Knife), the principal alternative to microsurgical resection for acoustic neuromas. Kondziolka, et. al., discuss and evaluate the results of a survey of 162 patients who underwent Gamma Knife for acoustic neuromas between 1987 and 1992.

With respect to Gamma Knife and Linear Accelerator (Linac), the jury is still out on which approach is superior. Gamma Knife has a longer track record, is available in the US and parts of Europe, and is administered in a single dose. The Linear Accelerator is just beginning to be used to treat acoustic neuromas, and it requires many doses over several weeks. It is, however, available in Canada. For those people who have decided on Gamma Knife, long and arduous battles with the respective Provincial Ministries of Health have been required to secure compensation for the cost of treatment outside Canada. Positive settlements have recently been made to residents of Alberta, BC and Ontario. It is still too early to tell if these successful settlements indicate a positive shift in government attitude, but there is a growing sense that compensation is possible. I encourage Contact Persons to include information on radiosurgery, both Gamma Knife and Linac, in their discussions with newly-diagnosed patients.

We welcome Mr. Glyn Smith as our new National Coordinator, replacing Ian McCormack, who has moved to a full-time position with another association. ANAC has benefitted from Glyn's expertise ever since he stepped into the position in early March.

Our national fundraising campaign has begun. Our recent grant from Health Canada was generous, but we need donations from the membership to bring our funding up to necessary levels. It is the positive attitude of our members and their willingness to contribute their financial support that has kept the Association going through these turbulent years, and this community spirit will help us develop the habit of annual giving.

Peggy Bray

ANNOUNCING

The Coalition of National Voluntary Organizations (NVO) Health Issues Division is pleased to announce the launch of a public ListServe for national voluntary organizations working in health.

This initiative is yet another way that NVO is making available to the voluntary health sector community in Canada.

This ListServe is public and has been established as a mechanism for discussions to take place "over the net" and to post information that you feel might be of interest to your colleagues. The Health Issues Division will post information about a variety of issues as a way of keeping you up-to-date and informed.

Anyone can join the listserve, so please feel free to advise colleagues and volunteers.

To subscribe, please go to NVO's website at www.nvo-onb.ca and complete the form. You will then receive a confirmation of your "subscription" by email.

See you all in cyber space!

Penelope (Penny) Marrett
Director, Health Issues
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(613) 238-1591, phone
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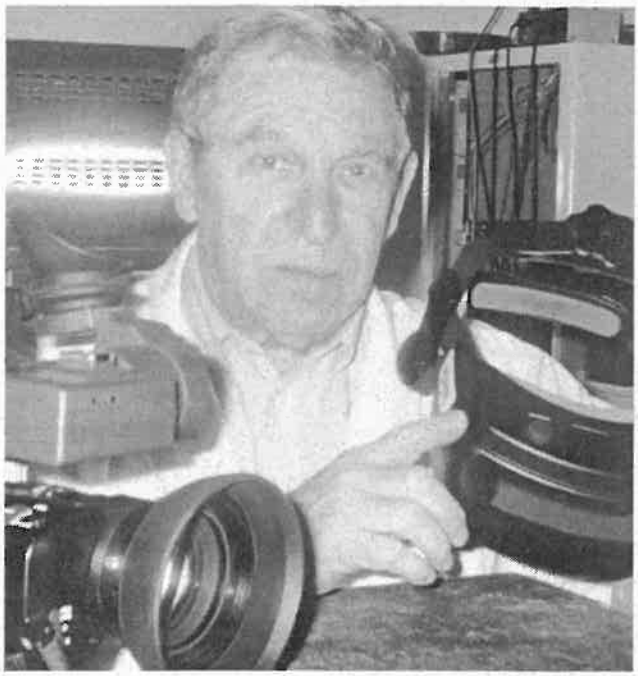
ANAC'S FIRST HONORARY MEMBER!



Henry Gordon Kitts, a long-time supporter of ANAC, has been named ANAC's first honorary member.

In 1982, Henry discovered he had an acoustic neuroma. He also discovered the power of the volunteer. Profoundly affected by the help given to him as he went through the difficulties and trials of treatment and recovery, Henry devoted himself to helping others as he had been helped.

His enthusiasm and energy led him to become a force in the founding of the Ontario chapter of the Acoustic Neuroma Association of Canada in 1985. As well as working to expand the local network in Ontario, Henry served on the Board of Directors and actively contributed to the growth of ANAC on a national level.

During his work for ANAC, Henry encouraged the Association to focus its efforts on education for the medical community and support services for patients and families who were dealing with this illness. He took it upon himself to develop educational tools for the Association, including a video presentation for professionals, and created annual seminars and conventions focusing on professional development, research, patient care and sibling support. One of his achievements in this area was serving as the coordinator for the 1993 ANAC Symposium in Toronto; he secured the exceptional conference facilities at MacDonald's Restaurants national headquarters for the event.

He also committed himself to supporting the special needs of health care professionals who specialize in acoustic neuroma and to this day volunteers his time to assist them when asked. In 1987 he became a part-time volunteer research assistant at the Vestibular Lab at St. Michael's Health Centre in Toronto, developing scientific laboratory tests on inner-ear imbalance which could be used as a testing mechanism allowing early diagnosis of several related illnesses.

On a more personal level, Henry was available to patients and their family members who were facing the challenges of surgery for acoustic neuroma. He helped them come to terms with their situation and welcomed continuing dialogue with them, including follow-up hospital and home visits and telephone calls.

By the mid-90's Henry decided to exchange his exceptionally active position in ANAC for a supporting role. We want to congratulate him and extend our appreciation for his many efforts over the years. He is indeed an exemplary member of ANAC.

Thanks Henry!

April 27, 1999
Dear Peggy:

What a lovely surprise to open your letter telling that I am the first ANAC honorary member. Be sure to send me a copy of the spring edition of *the Connection.*

It has always been a privilege to be associated with ANAC. I especially emjoyed working with the staff, and then I always felt that AN patients needed all the help they could get before and after the operation. I will still help any patient willing to call me.

I am still assisting Dr. Johnson at St. Michael's Hospital and we are now testing patients with equipment that we developed ourselves. I am confident that this test will detect an acoustic tumor in the early stages of growth ('early' meaning when the nerves to the eye are affected).

Thanks again for the good news!

Henry Kitts

Happenings!

Vancouver Island, B.C.

The Vancouver Chapter has had four meetings so far in 1999. At our February meeting, Adele Hern, a neuropsychologist, spoke about how the brain works and all the factors that go into an individual having an AN. Our meeting in March was well attended and included discussion with three individuals who are 'monitoring' their tumours. They appreciated talking to AN people about their experiences with both microsurgery and stereotactic radiosurgery. In June, we have been approved to put cans in liquor stores as fundraisers and for publicity. The Victoria chapter is looking for additional volunteers to help run this chapter, if you are in the area and interested, contact Susan.

Susan Rankin
1-250-595-0440

Campbell River, Vancouver Island, B.C.

17 people met on March 26th, eight of these were AN patients, two of whom are in the pre-treatment stage. We did not have a guest speaker, but there was a variety of literature to pass around.

Evalyn Hrybko
1-250-282-3269

Ponoka, Alberta

Although there are no active AN support groups in Alberta, Pat Greenwell has agreed to become the Contact Person for Alberta. Thanks Pat! Pat was this years' race co-ordinator for the annual fundraiser, The Great Human Race, held in Edmonton on April 25th.

Pat can be reached by mail at: 5302 - 57th St., Ponoka, Alberta, T4J 1M4, or by phone 1-403-783-4257, or e-mail at kgreenwell@ccinet.ab.ca

Wood Mountain, Saskatoon

There is no AN chapter in Sask, but Michael has been busy lately. He sent a 'letter to the editor' to two newspapers (one published his letter), and he has received several replies from people with head trauma. He's had an interview with a CBC reporter with the possibly of a follow-up sometime soon. He's very interested in getting chapters started in Regina and Saskatoon and is willing to serve as Contact Person.

Michael Klein
Box 3, Wood Mountain, SK. S0H4L0
phone 1-306-266-2115, or e-mail at mklein@sk.sympatico.ca

Brandon, Manitoba

Those interested in joining The Brain Tumour Support group, which includes some AN patients, should contact **Heather Hickmont at 1-204-725-0099**

Winnipeg, Manitoba

The Benign Brain Tumour Group is a small group that meets about every six weeks. Those interested should contact

Agathe, a social worker, at 1-204-237-2452.
Evalyn Hyrbko

Halifax, Nova Scotia

Acoustic Neuroma and Late Deafened Adult Support Group

We meet each month, except July and August, and have a monthly newsletter. Our membership is about 34, with average attendance varying from 10-25 people. December meeting – social evening, singing, accompanied by an accordion, we had a lot of fun. January meeting – no speaker, discussion of business [we require a laptop computer to accommodate our deaf members]. February meeting – guest speaker was Dr. A. Kirkpatrick, who spoke about AN and it's effect on each of us. March meeting – two members

Happenings!

Honorary Member

ANAC has had the pleasure of working with a number of individuals who have "made a difference," and whose involvement with the organization has helped it become what it is today. The title Honorary Member of the Acoustic Neuroma Association of Canada was established in the Winter of 1998 and is to be awarded to individuals who have contributed distinctive and distinguished service to the Association. If you are interested in nominating such an individual, please contact the National Office – (780) 428-3384

spoke, one who is in the process of having a Cochlear implant, and the other who described his experience with PEG tube feeding.

Leader is Ed Morrisey,
phone 1-902-434-1673
E-mail: ed.morrissey@ns.sympatico.ca

Montreal, Quebec

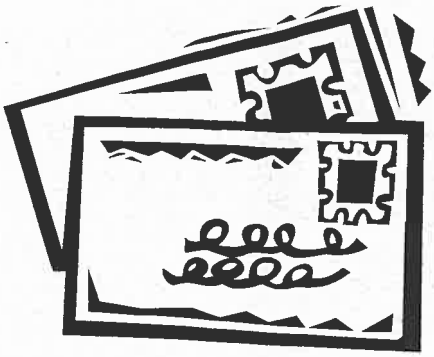
Sunday, March 28th, we had our spring meeting, with about 15 people in attendance. There were two speakers, Daniel Gemme, a massotherapist and Richard Legault, acupunctor. They informed us of their work in relation with pain in the back, neck, and head areas. It went well, was very interesting. Marie Legault and Marie Catherine Hamel organized the meeting.

For more information, call
Marie Catherine Hamel – home
514-334-7058 – work 514-283-9936

Kitchener/Waterloo, Ontario

The K/W Chapter held a pot-luck supper meeting on March 14th at the home of Trenny and Warren Canning. The agenda was jam packed, and included a financial report from our Treasurer, Allan Jones, distribution of guibor bandages to those members who were in need (at the last meeting the Chapter decided to use some of its funds to supply bandages to our members at no charge). We also purchased some soap products from one of our members and provided those interested with samples (the soap doesn't sting if it gets in your eye!). The two main agenda items included further discussion surrounding our annual garage sale (that was held on June 14th and 15th and raised more than $1,000),.and election of officers, effective June 1, 1999. As soon to be Past-President of the K/W Chapter, I would like to thank the members of our group for their enthusiasm and welcome Doug Specht (President), Lucinda Graval (Vice-President), and John Perry (Assistant Secretary) as members of the Executive. Continuing members include Allan Jones (Treasurer) and Dona Massel (Secretary).

For further information on the K/W Chapter, please contact:
Trenny Canning, 48 Ripplewood Crescent, Kitchener, ON N2M 4R8
E-mail: tcanning@secretariat.uwaterloo.ca



Mailbag

Mailbag letters express personal opinions and experiences only. ANAC does not endorse any product, treatment, physician, procedure, or institution. When a brand name occasionally appears it is for purposes of education. Always consult your physician before using any over-the-counter medication.

Dear Mailbag:

I would like to hear from AN people who have been diagnosed with a malfunctioning thyroid. As AN patients frequently experience fatigue, this bone weary feeling may have as much to do with a thyroid condition as an acoustic neuroma. During conversations, a few AN members have mentioned thyroid as a health issue for them. Recently, Trenny Canning and I attended a Health Canada Workshop in Ottawa. There were 10 of us from various National Voluntary Health Organizations having dinner together. As it turned out, 8 were being treated for thyroid disease. It piqued our interest enough to want to explore this health issue further. In the April issue of Chatelaine, the health news section reports that "one million Canadians have thyroid disease and half of them (mostly women over the age of 40) don't know it" (p.46). I'd really like to hear from you if you have already been diagnosed with thyroid disease. If not, but you're wondering, ask your doctor.

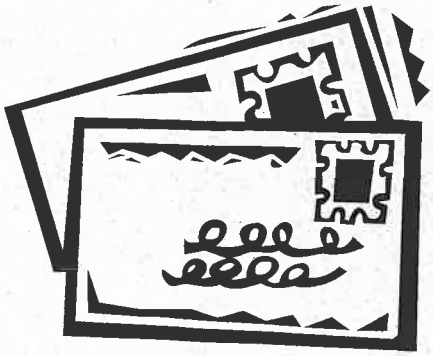
Naome Soleil
P.O. Box 19013
4th Avenue Postal Outlet
Vancouver B.C.
V6K 4R8

Dear Mailbag:

I had a 2.2 x 1.4 cm. Acoustic Neuroma removed in October of 1996, a fairly lengthy operation at Foothills Hospital in Calgary, Alberta. The tumor was finally diagnosed by an MRI scan as I had had a history of dizziness and balance problems for quite a number of years and had lost 70% of my hearing in my left ear. My tumor had been diagnosed about 1.5 years before my surgery but my doctors chose to monitor it as it was only 2 cms. When diagnosed, I had been informed that they grow slower in an older person. I am nearly 70 years old, but when the tumor began to grow more quickly than my doctors expected I was advised to have it removed. I will admit I was very apprehensive as I had read of quite a number of peoples' unfortunate experiences with their operations as written up in ANAC's newsletters. However, my doctors, neurosurgeon, Dr. M. Elizabeth MacRae and ear, eye and nose specialist Dr. Phillip S. Park, Otolaryngologist (head and neck surgery) convinced me I would probably come through the operation well, although there would be little chance of saving any hearing in my left ear.

I put my trust in their very talented and competent hands. I am so grateful and thankful every day to them both.

I never suffered one second of pain or discomfort, have not had any problems whatsoever – have no balance problems or facial problems – maybe occasional sight problems but not serious. I did lose all my hearing in my affected ear and I do have the same noise in my ear I had before the



Mailbag

operation (I had become accustomed to these both before the operation). I guess I have been one of the very fortunate ones and of course my growth was not as large as some, so I'm sure that helped but I would think the operation today must be much more sophisticated and exacting and less dangerous with so many terrible consequences than a few years ago especially with new technology. I would be very pleased to speak with anyone if they are going to have surgery and hope I could give them some peace of mind.

Alice Gammack
35 Glenview Dr. S.W.
Calgary, Alta
T3E 4H4

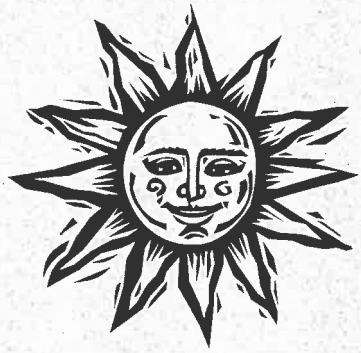
For a Special Occasion!

Instead of a present, how about a donation in someone's name to ANAC?

Dear Mailbag:

I would appreciate it if you could print this article in the next issue of *the Connection*. I have been aware for some time that my experiences were quite different from most and now, at 68, I am still working, involved and active. If this write up could inspire some individual to hang in there and get on with their life, I would be delighted. If you feel I could help in any other way please don't hesitate to contact me. I know I have said previously that I am not a fundraiser and much as I can apologize, that does not change the reality. I am however a professor of Human Biology and biochemistry and thus am knowledgeable, an experienced speaker, and if you can think of any way that I can volunteer my assistance, I will respond.

Ms Eleanore Van Norman,
Dawson College Montreal
133 Irvine Ave.
Montreal, Quebec H3Z 2K3



A Positive Outlook Wins the Day

For some time now I have been feeling guilty about not sharing my experiences following surgery for an acoustic neuroma two and a half years ago. I am feeling guilty because my experiences have not been negative. I am very aware of the differences created by an individuals' frame of mind. This is not the first disaster in my life with which I have had to cope. Fifty years ago after an accident as a teenager when the nerves to my arm got cut at the shoulder, I was told that my left arm would likely not function again. After long years of physiotherapy and swimming (which I took up as an exercise), my arm has regained approximately 95% or more of its functioning. I have a daughter with incredible back problems resulting from a broken vertebrae and years of gymnastics and dancing. Her doctor told her that he did not think that she would ever walk again without a cane

and today she is back on stage dancing. Is this mind set genetic or is it just familial? I don't know. All I know is that a positive outlook makes all the difference in the world.

When my neuroma developed, I had an experience that was very different from most other people. My symptoms developed literally overnight. I woke up one morning very dizzy and nauseated and sensed immediately that it was something drastic. I called a taxi to take me to the emergency where within two hours, they did a scan, put me in an ambulance and sent me to the neurological hospital. Within days they did a VP shunt (ventricular-peritoneal tube) and two months later operated to remove the tumour. Later when I had the opportunity to talk to other acoustic neuroma patients, I came to realize that I had been extremely lucky. Every other person I spoke with had had years of frustration visiting doctor after doctor without receiving a realistic diagnosis. They were often told to cut down the stress in their lives or to take classes in stress management. I did not go through any of this frustration. This may have helped me to have a more positive outlook.

When they operated to remove the tumour, it was more advanced than they had anticipated and the facial nerve was totally damaged. There has been no regeneration at all. However four months later, I was back at my college teaching. I would talk about it with my students because they were the ones who had to look at my face. I did not see it all day long. Students have told me over and over again that they do not have a problem with this. I have more concern than they do.

I am not suggesting that I don't have difficulties with an eye or with balance. The dizziness and the lack of balance never go away. However I don't think they even slow me down. I have never actually fallen (not even when I ski) and I have often suspected that I must look drunk as I walk down the street. I have been known to comment that perhaps I would feel better if I was drunk.

My neurologist had wanted to do a nerve transplant of some fibers from the next cranial nerve to my tongue to try to restore some activity to my facial muscles. I declined however because I feared it would negatively affect speech. I said that for me clear speech was more important than a straight face. He then referred me to a plastic surgeon who immediately (within a month) did a facial reconstruction. In this procedure, they take tissue from the leg, sew it under the skin on the face and then sew the sagging facial muscles up to it. I can not be a stronger advocate of this procedure. Although they had to go back a second time to center the lower lip, I now look almost normal. Only when I start to talk do you become aware that the muscles on one side do not work. My speech is clear.

Once I returned to work two years ago, I have only missed two days of teaching when the last lip procedure was performed. Through all of this, nothing has prevented me from dealing with the students and teachers with whom I work. Several people have said to me that they admire my guts. My reply is always that it is not guts. You are left with two choices: to cope or not to cope. In my family, it does not require any conscious thought. We simply cope. I hope you may recognize this characteristic in your family.

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Acoustic Neuroma Association of Canada

Annual Membership Fee: $32.00 (Tax receipt provided)

❒ New member
❒ Renewal

Member Fees support the work of ANAC plus provide three annual publications of our newsletter, *the Connection*. Also, members receive discounts when purchasing Guibor eye bandages.

Donation:

❒ Gold Circle ($1,000 or more) ❒ Silver Circle ($500 - $999) ❒ Bronze Circle $300 - $499)

❒ $200 ❒ $100 ❒ $50 ❒ $40 ❒ $_____ (other) *(Tax receipt for donations over $10)*

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I am ❒ present/former AN patient ❒ Family member ❒ Friend
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I am willing to: ❒ Yes ❒ No - have my address & phone number shared with other patients.
❒ Yes ❒ No - be contacted to give help locally when needed.

Acoustic Neuroma Association of Canada
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Naome Soleil and Trenny Canning at the conference in Ottawa

ANAC Participated in Conferences

International Physicians' Conference Held in Victoria, BC

The Vancouver and Victoria Chapters exhibited at the College of Family Physicians of Canada (CFPC) Conference in Victoria on May 14 and 15, 1999.

Our objective was to make known to the 450 physicians attending the conference the Association, its services, activities, and available literature so they, in turn, could pass this information on to their patients.

ANAC Victoria Chapter members and I staffed the booth in four-hour shifts. While we had relatively few (perhaps 40) visits from the 450 attendees, it was fun to catch up with ANAC friends.

Submitted by Wenda Deane, Vancouver Chapter

HAVING OUR SAY: A Federal Policy Development And Decision-Making Workshop – Naome Soleil, Vancouver

On March 5-7, 1999, Trenny Canning and I attended a Federal Policy Development and Decision-Making Workshop held at the Elgin Hotel in Ottawa. The workshop focused on a theme of building relationships between Health Canada and the voluntary health sector through partnership, advocacy, and coalition. Representatives from a wide-range of voluntary health organizations gained insight into how government works, whom to contact within the various levels of government to access information and cultivate support, and what inter-relatedness means when citizens actively participate in the policy and decision-making process. Key words highlighted in presentations were feasibility, accountability, collaboration, and generosity of spirit. Several speakers noted the value of respect, civility, and a 'thank you' in developing effective relationships in the democratic process. There was a panel discussion: "What can we learn from each other? Tim McClemmont, Hepatitus C Society of Canada, spoke on his organization's cross-provincial class action suit; Colleen Talbot, Spina Bifida and Hydocephalus Association, emphasized the importance of connecting with the "right" person in policy to raise public awareness of an issue, such as fortifying foods with folic acid as a preventative of Spina Bifida; Randolph Warren, Thalidomide Victims Association of Canada, gave a personal story of lobbying the government on behalf of approximately 120 thalidomide survivors on the grounds of compassionate assistance; and, Ken Kyle, Canadian Cancer Society, showed a video, "Lobbying for Lives: Lessons from the Front" and provided a balanced view for organizing a coalition effort and responding to opposition. The workshop was an invaluable opportunity to connect with other voluntary organizations and to become better informed about the responsibility NVHOs share with government in the policy and decision-making process. Sincere thanks to our hosts, Health Canada, and to the organizers and presenters who made it all happen.

ON BECOMING DEAF, by Dorothy Schuck

People really don't think I'm queer, they want me to hear, they shout in my ear.

Tell people to please speak slow, they really don't know.

I have to give them lots of tips, like, I can read lips!

I have a slate I carry with me for us to communicate, you see.

Being deaf has made me grow, for the beautiful people I've come to know.

Reach out, look up, and you will find, there's so much good in all mankind.

Be positive my friend, be true and kind, being deaf is a state of mind.

Funny Announcements from a Church Bulletin!

Thursday night – potluck supper, prayer and medication to follow!

For those of you who have children and don't know it, we have a nursery downstairs.

This afternoon there will be a meeting in the south and north ends of the church, People will be baptized at both ends!

This coming Easter Sunday, we will ask Mrs. Knotts to come forward and lay an egg on the altar!

Advertise in The Connection!

Do you own a business or provide a service that could benefit from advertising in *the Connection*? If you are a member of the Association, or would like to become one, and want to reach about 1200 AN patients, their families and friends, and medical professionals, call 519-579-4855.

It reaches 1200 AN patients, friends and family, not to mention members of the medical community!

- One page = $185
- One half page = $100
- One quarter page = $50
- Business Card = $25

New Donation Category - Membership

Membership in the Acoustic Neuroma Association has many benefits, one of which is receipt of *the Connection*, an important vehicle for disseminating information and one of ANAC's *raisons d'être*. ANAC is concerned that the recent increase in membership fees to $32.00 per year may have made it financially difficult for some individuals to join. If you, or someone you know, are in this situation and would like to join the Association, please contact the National Office and indicate that you would like to be considered for membership subsidy; please be assured that your confidentiality will be respected.

Members, if you wish to help out in this respect, a donation under "Membership" would be appreciated and welcomed.

PLEASE NOTE:

Funds donated through this category will convert to "General Donations" in the event that there is no recipient identified.

ht

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