

the Connection

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**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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*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
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Articles on any treatment method published
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NF-2 Update

by
M. Priscilla Short, MD
Division of Pediatric Neurology
University of Chicago

This brief report summarizes
Dr. Short's responses to some of
the commonly asked questions
about NF-2.

What is NF-2?

NF-2 is a relatively rare genetic
condition which causes tumours in
the nervous system. These include
schwannomas from the schwann
cells that surround nerve fibres,
meningiomas from the
meningothelial cells located
in the covering over the brain and
spinal cord, and ependymomas
that arise from ependymal cells
that line the ventricular system in
the brain and the central canal in
the spinal cord.

NF-2 can occur without family
history, or NF-2 can be inherited
from an affected parent. Nearly
half of the cases of NF-2 are
results of new mutations and are
not inherited. Any affected person,
however, has the risk of passing it

on to his/her children (each child
has a 50% risk).

If I have a unilateral acoustic neuroma (vestibular schwannoma), should I worry about having NF-2?

No. Patients with NF-2 have
bilateral acoustic neuromas. A
variant of NF-2 may be the patient
who has a unilateral acoustic
neuroma and other tumours, such
as meningioma, but this
relationship has not been
established.

What is the status of NF-2 DNA diagnostic testing?

NF-2 DNA diagnostic testing is
available through commercial
DNA testing laboratories. Your
physician can order the test, but
your insurance may not cover the
expenses. [Editor's Note: This
information applies to the US;
your physician may be able to
provide more information on
testing available in Canada].

DNA testing for NF-2 is still a problematic issue from a technical standpoint, with at present a large false negative rate (e.g., the inability of the lab to find the mutation in the gene for a person who clearly has NF-2 on the basis of the presence of the defining tumours).

When should a test be done to determine if a person has the NF-2 gene?

This is a difficult and very sensitive issue that remains unresolved. We strongly recommend counselling with the individual and his/her family prior to testing as well as afterward to discuss all aspects of this problem.

If there is a family history suggestive of NF-2, testing may be

appropriate. Detecting NF-2 early, especially in children before the acoustic tumours are large, may make it easier to remove a tumour without losing hearing. Making a diagnosis of NF-2 in a seemingly unaffected child, however, may have some negative as well as positive aspects.

There are other issues that need to be kept in mind when requesting NF-2 DNA diagnostic testing. The DNA testing results will be negative or positive. At present, there are substantial numbers of people with NF-2 in whom, as yet, we have been unable to find mutations. A negative result for someone at risk where the mutation is known means that person is not affected and does not need to have any further screening tests, such as hearing tests or MRIs

for the detection of NF-2 related tumours. A negative result in a person without a family history means that the mutation may not have been found using the current techniques. The research labs are still working on the problem of not being able to identify mutations. Hopefully, in the near future, we will be hearing about their efforts to confront this limitation to current testing. A positive result means that person will manifest symptoms related to tumours associated with NF-2, but the clinical problems may not follow exactly the problems related to tumours of other affected family members. In addition, the natural history of NF-2 may be dramatically altered in the future with the advent of presymptomatic testing and the development of new therapies.

The Acoustic Neuroma Association of Canada ANNUAL GENERAL MEETING

WHEN - Saturday March 4, 2000

WHERE - Howard Johnson Harbourside Inn, Nanaimo, Vancouver Island. The hotel is close to both the ferry and the bus terminal.

COST - There is no charge to attend or participate in the sessions or the AGM. Members are responsible for covering the costs of travel, accommodation and food.

Although planning is still underway, the Committee

responsible for the AGM believes that an AGM is important for several reasons: to conduct the business of the Association, and as an opportunity for members across Canada to meet each other in person and to provide them with an opportunity to discuss common issues. The AGM schedule has been arranged to allow this to occur (i.e., various informal gatherings throughout the weekend). Speakers from the medical profession have been arranged for Saturday morning, with the AGM proper being held in the afternoon. Sunday morning

will be geared toward local chapter development and the development of a Volunteer Manual.

Make plans NOW to come to Nanaimo. Come early or stay on after the conference and enjoy the mild weather and pleasant surroundings of Vancouver Island or stop off in the metropolis of Vancouver on your way home.

Further information will be mailed to all members in early January and updates will be regularly posted on the Association's website (www.anac.ca).

Steriotactic radiosurgery in the management of acoustic neuromas associated with neurofibromatosis Type 2

Brian R. Subach, M.D., Douglas Kondziolka, M.D., F.R.C.S.(C), L. Dade Lunsford, M.D., David J. Bissonette, PAC, M.B.A., John C. Flickinger, M.D., and Ann H. Maitz, M.S.

Department of Neurological Surgery, Radiation Oncology, and Radiology, and the Centre for Image Guided Neurosurgery, University of Pittsburgh Medical Centre, Pittsburgh, Pennsylvania.

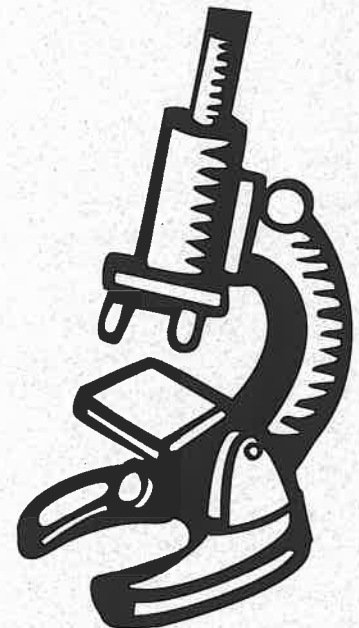
[Editor's Note: This paper was referred to the National Office by Dr. Kondziolka, a member of our Medical Advisory Board. A copy of the complete article is available from the National Office.]

OBJECT. Stereotactically guided radiosurgery is one of the primary treatment modalities for patients with acoustic neuroma (vestibular schwannomas). The goal of radiosurgery is to arrest tumour growth while preserving neurological function. Patients with acoustic neuromas associated with neurofibromatosis Type 2 (NF2) represent a special challenge because of the risk of complete deafness. To define better the tumor control rate and long-term functional outcome, the authors reviewed their 10-year experience in treating these lesions.

METHODS. Forty patients underwent stereotactic radiosurgery at the University of Pittsburgh, 35 of them for solitary tumors. The other five underwent staged procedures for bilateral lesions (10 tumors, 45 total). Thirteen patients (with 29% of tumors) had undergone a median of two prior resections. The mean tumor volume at radiosurgery was 4.8 ml, and the mean tumor margin dose was 15Gy (range 12-20 Gy).

The overall tumor control rate was 98%. During the median follow-up period of 36 months, 16 tumors (36%) regressed, 28 (62%) remained unchanged, and one (2%) grew. In the 10 patients for whom more than 5 years of clinical and neuroimaging follow-up results were available (median 92 months), five tumors were smaller and five remained unchanged. Surgical resection was performed in three patients (7%) after radiosurgery: only one showed radiographic evidence of progression. Useful hearing (Gardner-Robertson Class I or II) was preserved in six (43%) of 14 patients, and this rate improved to 67% after modifications made in 1992. Normal facial nerve function (House-Brackmann Grade I) was preserved in 25 (81%) of 31 patients. Normal trigeminal nerve function was preserved in 34 (94%) of 36 patients.

CONCLUSION. Stereotactically guided radiosurgery is a safe and effective treatment for patients with acoustic tumors in the setting of NF2. The rate of hearing preservation may be better with radiosurgery than with other available techniques.



Acute hearing loss following fractionated stereotactic radiosurgery for acoustic neuroma

J Neurosurg 89:321-325, 1998

Steven D. Chang, M.D., Joseph Poen, M.D., Steven Hancock, M.D., David P. Martin, M.D., and John R. Adler Jr, M.D.

Department of Neurosurgery and Radiation Oncology,
Stanford University Medical Centre, Stanford, California

[Editor's Note: The following paper is reprinted with permission of The NF2 Review, Winter 1998. Vol 5, Issue 3].

Two cases of acute hearing loss are reported following fractionated stereotactic radiosurgery for acoustic neuroma. Both patients had neurofibromatosis type 2 and were treated with a peripheral tumor dose of 21 Gy delivered in three fractionations (7 Gy each) with a minimum interfraction interval of ten hours. One patient who had previously undergone surgical resection of the treated tumor presented with only rudimentary hearing in the treated

ear secondary to an abrupt decrease in hearing prior to treatment. That patient reported total loss of hearing before complete delivery of the third fraction. The second patient had moderately impaired hearing prior to treatment: however within 10 hours after delivery of the final fraction, he lost all hearing. Both patients showed no improvement in response to glucocorticoid therapy. Possible explanations for this phenomenon are presented.

COMMENT

John R. Adler, Jr. MD.
Professor of Stanford
Neurosurgery
Department of Neurosurgery
Stanford, CA 94395-5327

This paper describes a previous unrecognised complication of stereotactic radiosurgery for acoustic neuroma. Although gradual hearing loss after radiosurgery has been reported before, sudden deterioration is both undescribed and represents somewhat of a curious side effect of radiation.

Radiation is generally believed to kill a tumor slowly by damaging cellular chromosomes making it impossible for the cells to reproduce. By virtue of the fact that the damage to normal tissues was near immediate in the 2 patients being reported, it would appear that the effects of larger radiation doses, as are often administered

with radiosurgery, may function differently than lower doses conventional radiation therapy. This observation has implications for both understanding the relatively efficient mechanism by which radiosurgery can abate tumors, including AN, and patient consent. With respect to the latter, it is important that a patient with acoustic neuroma who is about to undergo radiosurgery, understand that there is a risk of immediate hearing loss in the treated ear. In particular this message may have special meaning for patients with NF2, since the 2 patients that suffered this complication both had NF2.

Despite the above newly recognised complication of radiosurgery, it is important that AN patients keep this observation in perspective. The 2 patients reported in this paper were culled from the more than 100 patients with acoustic neuroma

in whose radiosurgery I have been involved. For the vast majority of patients, including those with NF2, stereotactic radiosurgery, either single or multiple fraction, promises to preserve hearing and other cranial nerve function. Also it is worth noting that in one of the patients who suffered this complication, hearing was barely detectable in the affected ear. This observation may argue for using radiosurgery, and I believe in some measure of fractionated treatment, earlier in the course of the disease, before too much hearing is lost.

Although our understanding is incomplete, there is a growing clinical experience using radiosurgery to treat AN. When this experience can be conscientiously analysed, in published peer-reviewed medical literature, I believe that many of these questions can be answered.

[Editor's Note: Dr. Douglas Kondziolka, MD., M.Sc, FRCS(C), Professor of Neurological Surgery, Department of Neurological Surgery, University of Pittsburgh, a member of ANAC's Medical Advisory Board, was asked to comment on the above article. Dr. Kondziolka's comments follow].

Increasingly, stereotactic radiosurgery is being used in order to preserve hearing in patients with solitary acoustic neuromas or in patients with neurofibromatosis type II. Using Gamma Knife, a single fraction of radiation is delivered to the tumor using precise image guidance. The goal is to conformally irradiate the

tumor yet deliver a very low dose to the surrounding nerves. Others with linear accelerator systems have attempted fractionation techniques in order to irradiate, in a less conformal way, the tumor yet still try to preserve hearing or facial function. In this report, two patients lost hearing acutely in the setting of NF II. The Stanford group delivered a tumor margin dose of 21 Gy in three fractions. The dose necessary to control an acoustic tumor and yet preserve hearing is unclear.

At present we use a tumor margin dose between 12 and 3 Gy when hearing preservation is attempted. In doing so, six of the last nine patients with NF II who had good

hearing before radiosurgery maintained it afterwards. Hearing preservation rate with the Gamma Knife in patients with solitary acoustic tumours is currently above 80% using similar doses. There is no doubt that hearing can be lost using any technique. When radiosurgery is performed, it should be done by an experienced group using high resolution imaging, conformal dose planning and an appropriate device. Our goal as physicians and patients has been to improve the chance for retaining good-quality hearing. Ten years ago, hearing preservation was a rarity. Currently, good hearing is preserved more often than it is lost.

GAMMA KNIFE ONTARIO COURT OF APPEAL DECISION

The National Office recently received a copy of the Ontario Appeal Board's 1998 ruling regarding paying for Gamma Knife treatments in the United States for acoustic neuroma patients residing in Ontario. In summary, the Board stated that "Stereotactic Radiosurgery by fractionated Linac and Gamma Knife are not equivalent treatments for an acoustic neuroma." The justification was based on:

- the long-term follow up and experience in the treatment of ANs with the Gamma Knife
- the established efficacy of the Gamma Knife
- the technical qualities of the Gamma Knife that make it ideally suited for treating such indications as AN
- the patient's preference for treatments in a single session.

There are also some references to the Acoustic Neuroma Association in this report.

One patient was quoted in the report as stating that she was told "there were no other options, other than to have the tumor surgically removed." She contacted the Acoustic Neuroma Association and attended a meeting. Through ANAC information, she read about Gamma Knife radiosurgery.

One of ANAC's publications was also quoted in the report to provide some statistics about AN.

The above case shows that ANAC does have an important role to play in the treatment of acoustic neuromas. We need to keep on producing and updating our literature and, as the quote above demonstrates, we need to

keep our local chapters operational. They are an important part of our Association as they allow members to communicate and share experiences and opinions.

GAMMA KNIFE NEWS

It has come to our attention that the Ministry of Health in Ontario has decided to invest in a Gamma Knife. A number of hospitals have been asked to make submissions to the Ministry. We will keep you informed as we hear more news.

There has also been talk of a private facility opening in British Columbia. This has not been announced yet and appears to be moving forward slowly.

President's Corner

December 1999

As 1999 draws to a close and the new century approaches, I want to take this opportunity to thank everyone who has contributed to ANAC over the past years. In particular, I'd like to mention, at the national level, three members of the Board of Directors who have decided to move on to other endeavours. Jackie Diels of McFarland, Wisconsin, who coordinated the Neuromuscular Retraining Workshops for physiotherapists, and Irma Arnold of Wasaga Beach, Ontario, who, for many years, has been a fount of information on stereotactic radiosurgery and who was instrumental in producing the patient information handbook on stereotactic radiosurgery.

Both Jackie and Irma will continue to act as a resource for their areas of expertise. The third is Ruth Harris of Plattsville, Ontario, who has supervised our finances and provided the Board with an objective point-of-view.

We wish them well, and at the same time I want to remind you that our Board always needs and welcomes new people with fresh ideas. The Directors meet four times a year by teleconference and do much of their work through committees focused on four broad areas: *the Connection* newsletter, Chapter Development, Revenue Generation, and Information Dissemination & Website Development.

We've also had several changes at the local or chapter level. In Kitchener-Waterloo, Trenny Canning turned over the leadership to Doug Specht. When Susan Rankin returned to mainland BC, the Victoria chapter elected Rose Christiansen as president. An opportunity exists in the Vancouver chapter since Wenda Déane, President, plus other executive members have moved on. Gordon Miller who has been the contact person for mainland BC, has turned this responsibility over to Naome Soleil. On behalf of the Association, I express my thanks and appreciation to those leaders who are moving on.

This issue of *the Connection* has some news bulletins that I want to bring to your attention.

- Gamma Knife, the non-invasive radiosurgery treatment, is coming to Toronto. Thanks go to Michael Delegrande, Irma Arnold, Dr. Charles Tator and many others for their tireless efforts.
- Modified Linear Accelerator, another form of non-invasive radiosurgery is available at hospitals in Quebec, Ontario and BC.
- BC Neurofibromatosis Association plans to develop into a national association.
- ANAC Annual General Meeting will be held in Nanaimo, BC on March 4/5, 2000.



Midnight of December 31 will mark a milestone that we all share. Your Association has worked hard to prepare itself. Our systems are Y2K compliant, the organizational systems have been streamlined and the fundraising campaign raised – and the seed planted for annual giving. Are you ready? The strength of our Association comes from its members, from the efforts and hard work of the individuals I have mentioned and from the many others who participate. Their contributions challenge each one of us to think about what we can do to become more involved in ANAC.

Have a happy holiday and I'll look forward to seeing you at the AGM!

Peggy Bray

CHRISTMAS GIFT DILEMMA?

Don't know what to buy for that person who has everything?

No need to fight the crowds at the mall, no tired feet, no last minute rush. Give a gift that will really count!

Make a donation, in their name, to ANAC or buy them a membership (\$32 for one year).

It's quick and easy. For donations of \$10 or more, the Association will send your friend a Christmas card notifying them that a donation has been made in their name (and by whom) or, informing them that a membership has been purchased in their name and by whom. You will receive a tax receipt.

All donations and membership requests must be received prior to December 16th to ensure that a Christmas card will be delivered on time.

Fax your request to 780-425-8519



DON'T QUIT

When things go wrong, as they sometimes will,
When the road you're trudging seems all uphill,
When funds are low and the debts are high,
And you want to smile, but you have to sigh,
When care is pressing you down a bit,
Rest if you must, but don't you quit.

Life is queer with its twists and turns,
As every one of us sometimes learns,
And many a person turns about,
When they might have won had they stuck it out,
Don't give up though the pace seems slow,
You may succeed with another blow.

Often the struggler has given up when he might
have captured the victor's cup,
And he learned too late when the night came down,
How close he was to the golden crown,
Success is failure turned inside out.
So stick to the fight when you're hardest hit,
It's when things seem worst that you mustn't quit

Author unknown

ARTICLES ABOUT NEUROFIBROMATOSIS TYPE 2

[Editor's Note: The following articles are printed by permission of "NF2 Review" and appeared in Winter 1998, Vol 5, Issue 3.]

Am J Otol 1998 Sep;19(5):638-43

Hearing preservation in neurofibromatosis type 2

Slatter WH 3rd, Brackmann DE, Hitselberger W
House Ear Clinic & House Ear Institute, Los Angeles, California 90057-9927, USA

OBJECTIVE: The aim of the study was to provide a clinical review of the middle fossa approach for hearing preservation in patients with neurofibromatosis type 2.

STUDY DESIGN: The study design was a prospective case review.

SETTING: The study was conducted at a private practice tertiary neurological referral centre.

PATIENTS: Eighteen patients diagnosed with NF2 underwent 23 middle fossa procedures between 1992 and 1996 for removal of an acoustic neuroma. The nine males and nine females ranged in age from 11-73 years with a mean age of 28 years. Tumor size ranged from 0.5-2.5 cm with a mean of 1.1 cm.

MAIN OUTCOME MEASURES:

House-Brackmann facial nerve grade was measured. In addition, hearing level was classified both by the American Academy of Otolaryngology-Head and Neck Surgery criteria for reporting results of hearing preservation level (15dB/15%).

RESULTS: Measurable hearing was preserved in 65%, 48% within 15dB of preoperative pure-tone average (PTA) and within 15% of preoperative discrimination. Bilateral hearing preservation occurred in five patients. Excellent facial nerve function (House-Brackmann grades I-II) was obtained in all patients with normal preoperative facial nerve function.

CONCLUSIONS: In this series of patients with NF2, outcomes in hearing and preservation of preoperative facial nerve function are similar to results seen in patients suffering a sporadic unilateral acoustic neuroma. However, early intervention is crucial in obtaining such favourable outcomes.

Fortschr Neurol Psychiatr 1998 Jun;66(6):271-7

[Neurofibromatosis versus schwannomatosis]

[Article in German] Mautner VF, Schroder S, Pulst SM, Ostertag H, Kluwe Neurologische Abteilung, Ochsenzoll, Hamburg

Neurofibromatosis Type 1 and 2 (NF1 and NF2) are different forms of neurofibromatosis, well defined both clinically and genetically. In absence of typical clinical features of NF1 (cafe-au-lait-spots, cutaneous neurofibromas, Lisch-nodules) or NF2 (vestibule schwannoma) clinical classification is often not possible. Neurofibromas are more common in NF1 and

schwannomas are typical for NF2, but pathological histology does not provide sufficient evidence for diagnosis. We describe 14 patients who present with the clinical picture of multiple spinal tumours. Detailed family history, exact clinical examination including and ophthalmological led to the diagnosis of NF2 in four cases. Mutation analysis confirmed the diagnosis of NF2 in one case by identification of a 163 base pair deletion in the NF2 transcript. To investigate the expression of schwannomin and neurofibromin we stained tumour paraffin sections of six patients with antibodies against peptides of the NF1 and the NF2 protein. Based on preserved immunoreactivities we were able to exclude diagnosis of NF1 in three and NF2 in two cases. In four patients the clinical symptoms could confirm the diagnosis of schwannomatosis. Combining the results of clinical, neurogenetical and immunohistochemical examinations we could diagnose NF1 and NF2 in ten patients in total. Immunoreactivity led to the suggestion of NF2 in two patients; the other two patients whose tumours were not stained so far, could as yet not be classified for NF.



H a p p e n i n g s !

Nova Scotia

ACOUSTIC NEUROMA and LATE DEAFENED ADULT SUPPORT GROUP

One of our members, Jack Fry, passed away in Sept. Per the family's request, donations were made to our support group; more than \$100 was received. Several members attended the funeral.

At our September meeting, Dave Spencer provided the group with an update of how his cochlear implant was working. He told us that he had made three visits to Ottawa, where his operation took place. First, for the assessment, then for the operation, and then to set the audio. Dave told the story of his being in a cafeteria and hearing a 'crumbling' noise, and, after looking around, came to the conclusion that it was the sound of his chewing his lunch - french fries! Our laptop has needed to be replaced for some time. One has now been donated, and was used and appreciated during our during September meeting. At our October meeting we had a speaker from the Brain Injury Association, to talk about the challenges its members face (marriage breakdown is common)

when one sustains a brain injury. Our next meeting is planned for November.

Ed Morrissey,
106 Spring Ave.,
Dartmouth, N. S. B2W4C5
ed.morrissey@ns.sympatico.ca

London, Ontario

In September, Doug Flood and his wife Eleanor, who is NF2, celebrated their 48th wedding anniversary and his 70th birthday; a celebratory event was held at the Guy Lombardo Museum. There was a charge for people to attend which raised \$500 for ANAC. Way to go! Congratulations to Doug and Eleanor on these milestones!

Ponoka, Alberta

At a recent meeting, with people interested in rejuvenating the Edmonton chapter, the following ideas resulted: 1) Rather than duplicating resources which are already in place, we propose to find out if there are support groups dealing with, for example, hearing impairment, facial paralysis, and benign brain tumours, and see if we can collaborate with them. Our intent is to find out what is available and

make that information known to the membership. 2) We want to update our local membership list, to include e-mail addresses, and to ensure that all names on the list are, in fact, interested in being invited. 3) We intend to include a brief outline and description of Acoustic Neuroma and contact information in as many free publications as we can find.

Pat Greenwell
kpgreenw@telusplanet.net

Vancouver Island, Courtenay

On September 17th, nine people gathered at a restaurant. We didn't have a guest speaker and there were no new members in attendance.

Meetings rotate between Courtenay and Campbell River, twice yearly. It is always great to be together with our extended family! We leave, having shared with, and encouraged each other. One lady in our group indicated that she enjoys cooking and, next time, would like to have us all over to her home for a meal. Our mouths' are already watering!

Evalyn Hrybko
1-250-282-3269



H a p p e n i n g s !

Nanaimo, Vancouver Island

On June 5th, 26 people met at the Howard Johnson Harbourside Hotel. Our guest speaker was Dr. Elizabeth Cornock, an ophthalmologist from Comox. She did an excellent presentation followed by a good question/answer period. Another meeting was held at the same hotel on October 23rd. This meeting was attended by 25 people from Victoria, Duncan, Nanaimo, Parksville, Comox, Sayward, and the Vancouver area. The guest speaker was Donna Stewart, audiologist. She spoke of different "hearing devices" available, and gave practical every-day ideas of coping with hearing loss in different situations. There were five pre-treatment AN people present at this meeting, which prompted a good sharing of information from those who have or are going through similar experiences. It is all of us together who "choose" to come and to give of ourselves, to share, and to learn from each other.

Evalyn Hrybko
1-250-282-3269

Victoria, Vancouver Island

A meeting, attended by seven people, was held on September 25th, at the Holiday Inn. We reviewed last year's events, and elected our new executive, as follows: Rose Christensen - President; Art Finlayson, Treasurer; and Beth Smith, Social Coordinator. Meetings are planned for the following dates - Nov. 15, Jan. 17, March 20, and May 15. A Christmas social is also anticipated. Present projects and aims for the new year are;

- 1) updating and distributing our mailing list to Victoria AN members;
- 2) fund raising, especially donation cans and literature in places of business;
- 3) putting together a leaflet, to be distributed to doctor's offices, identifying the support and information available through ANAC and AN Victoria. On October 12th, a neuroscience fair was held at Victoria General Hospital. AN Victoria was represented by Beth Smith, Linda Main, and Linda Beare.

Rose Christensen
1785 Emerson, Victoria, B. C.,
V8R2C2
1-250-598-9693

Kitchener/Waterloo, Ontario

At the end of June three people met to discuss old and new business as well as to discuss the success of a garage sale. Dates have been set for meetings in the coming year, starting in September. There was also discussion about the direction and future of our chapter in coming months. At the meeting in September, held on September 12th (10 people in attendance), at the Laurel Church Centre in Waterloo, Sue McCarter and Joyce Haynes from the Canadian Hearing Society spoke about the benefits of learning to lip read. Also at that meeting, the Chapter agreed to donate \$1,000 to the National Office for the 1999 Fundraising Campaign. This money was raised through the Chapter's annual garage sale. Stay tuned for information on our next meeting. If you wish to be invited to these meetings, please drop a note to Doug Specht.

Doug Specht
dspecht@golden.net



H a p p e n i n g s !

Vancouver Chapter News

Effective August 31, 1999, I resigned as President of the Vancouver Chapter. Despite requests, I have unfortunately been unable to find anyone to assume the Presidency. At a meeting on October 28, the Vancouver Executive members announced they were unable to assume additional responsibility. As a result the painful decision was taken to fold the Vancouver Chapter for the time being, pay all outstanding accounts, and forward the remaining funds (approximately \$3,800) to the National Office to use for the continued maintenance and support of the ANAC website. I am proud of the achievements of the Vancouver Chapter over the years. If you want to reconstitute this chapter, I urge you to "step up and volunteer" to make it happen! Call the National Office or Evalyn Hrybko with expressions of interest.

Wenda Deane

Saskatoon, Saskatchewan

"Good morning Evalyn. Just a short note to let you know that our meeting which was held on Tuesday night was

a great success. I had sent out 16 letters and 9 attended along with 5 spouses. One woman has not had her surgery yet and she called to say she was anxious to hear about the meeting and wanted to be able to be in touch following her surgery. We had a good cross-section of people with one individual who had just had surgery in July of '99 and then others who have had surgery since 1992.

It was a good "friendly get to know each other" meeting and we did share our experiences and concerns about the surgery and the follow-up. I appreciate the information you sent me and we will use that at our next meeting in the New Year. All were in agreement that they wanted to hold another meeting and I am sure at that time we will decide to have a support group of some type. Most thought at this point, that meetings 3 or 4 times a year would be ample, with reference phone numbers provided, to be able to contact each other at other times. Michael Klein from Wood Mountain, who is the Saskatchewan representative was at the meeting and he shared his experiences and frustrations, and what he has done to promote information about Acoustic Neuroma through the

news media and health districts. It was a very informal evening with each one of us introducing ourselves and sharing our date of surgery and outcomes. All left the meeting with a feeling of closeness. A couple of fellows had really not had any contact with anyone who had undergone this surgery and they were particularly thankful for the meeting. Thanks again for your interest and we will be in touch. Doug and Marilyn."

Doug McLeay
mcleay@home.com

Winnipeg, Manitoba

The Benign Brain Tumor Support Group of Manitoba was formed in 1988 when the social worker on the neurosurgery ward at St. Boniface Hospital encountered several brain tumour patients who expressed a wish to talk to others like themselves. Since that time, the group has grown substantially, with attendance at meetings ranging anywhere from six to more than 30 people. The meetings have always been open to anyone interested, whether a person who was just diagnosed, a person recovering from treatment, family members or friends. The group



H a p p e n i n g s !

meetings were a scheduled function of the social worker on the neurosurgery ward. In the Spring of 1999, all Winnipeg Hospitals experienced a major re-organization and, as a result, the neurosurgery ward was moved from St. Boniface Hospital to the Health Sciences Centre. This move took place in late spring and since then, all surgeries for brain tumors have taken place at the Centre. Although our members had been assured that the group would continue under the direction of the Social Work

Department at Health Sciences, there have been major delays in getting set up again. The latest news we have received is that a meeting will be organized for December, but at this time we have not been given specifics as to date, time or place. Questions concerning the group and meetings should be directed to the Social Work Department at Health Sciences Centre, telephone number: 204-787-1287.

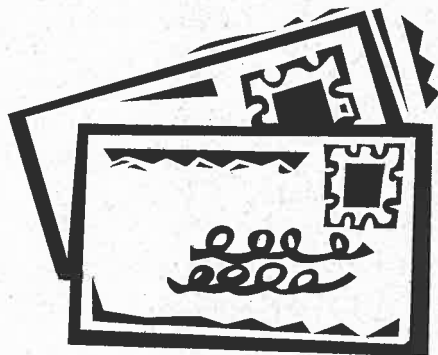
Leslie Sutherland
204-888-3438

The following people have agreed to serve as Contacts for their area, and are interested in establishing or rejuvenating chapters in these areas.

If you want further information, or are interested in helping them get established, please contact:

Winnipeg, Manitoba - Leslie Sutherland, Benign Brain Tumor Group (204-888-3438)

Brandon, Manitoba - Heather Hickmont, Brain Tumor Support Group (204-725-0099; fax: 1-204-729-3331)



M a i l b a g

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 product. Anyone wishing to respond to a comment or question in the Mailbag is encouraged to do so. Please copy your response to the National Office in the event that it can be used again for future requests for information.

Dear Mailbag:

My name is Annette Wright and I had surgery to remove an acoustic neuroma in London, Ontario, in March 1997. I visited your web page but the section on Dental is "Under Construction". I don't know if this has anything to do with my surgery but I experience

toothaches on both sides of my mouth with the pain sometimes radiating into my tongue. I've been to several dentists and dental specialists who find no cavities or cause for these pains. Have any of your members had similar problems after surgery?. Please let me know if you can shed any light on my problems. Thank you,

Annette Wright
aewright273@hotmail.com

Dear Mailbag:

Hi, my name is Glennis. I am wishing to write to people overseas who have had an acoustic neuroma. I had my AN operation on the 6th of June 1996 followed by more operations to fix two CSF leaks and meningitis. I was in hospital, on and off, for five months. Here I am three years later still improving and helping other people who have had an AN. I have met many lovely people in Brisbane through our support group and we have some very interesting guest speakers who come to our meetings to speak to us and keep us informed on what is new with acoustic neuromas. My interests are interior decorating, gardening, travelling, flying (don't actually fly but love it!) and collecting plane charms. I enjoy swimming and going to the beach and picnics. I am in my early 40's with two girls in their early 20's. My career is with the ANZ bank - one of our largest banks. This career of mine is still in the trial stages as I am still trying to cope with my hearing loss (noisy world out

there) and my balance problems. I get very tired and come home exhausted some days. I hope to improve as time goes on. I hope you will pass this letter on to anyone who is interested in corresponding with me as I enjoy meeting people and would like to hear from any of your members.

Glennis Wallace
Ky-Mara-Glen
9 Somerton Street
Bracken Ridge, Brisbane
Queensland 4017
Australia

Dear Mailbag:

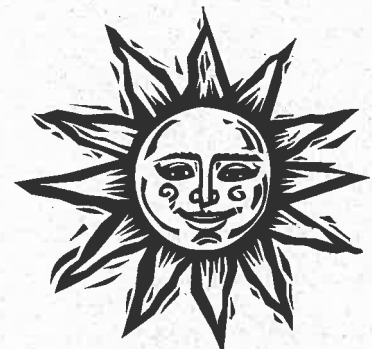
Three years have now passed since my AN surgery, and my ongoing battle with fatigue leaves me increasingly frustrated and impatient. As a wife, mother of two sports-minded boys, aged 8 and 12, and a full-time practicing lawyer, it is not surprising that I am weary. However, I would prefer to continue the active lifestyle that I had before surgery and would appreciate information about ways to manage my fatigue. It has been suggested to me that the medication, Ritalin, which is commonly used by children with attention-deficit hyperactivity disorder, might help boost my energy level and increase my focus on days when my schedule is particularly demanding. I am wondering whether there are any other AN patients suffering fatigue who have tried Ritalin, and if so, I would appreciate hearing about their experience. Also, if there are any doctors reading this inquiry who would like to

make a comment, it would be very helpful.

Suzanne Johnston
1598 Heritage Way
Oakville, Ontario L6M 2Z5 Email:
sjohnston@mcleankerr.com

Dear Mailbag:

Hi! My name is Dave Spencer. I am a member of the Acoustic Neuroma and Late Deafened Adult Support Group of Halifax, Nova Scotia. Although I am not AN, I share a common bond with many of the members, as I am profoundly deaf. I really enjoy the support and friendship within the group as well as the outside connections this group has opened up for me. At 11 years of age, I began having trouble hearing some sounds. My mother had a hearing problem which, unfortunately, I and my two daughters have inherited. Our loss is typically in both ears. The loss usually starts as very moderate, and then progresses to being profound. Even in elementary school, I remember not being able to hear some voices correctly. I developed the ability to lip read by watching a person's mouth movements. In high school, I missed a lot of



A Positive Outlook Wins the Day

instructions when the teacher turned towards the board. In my early 20's, the phone was no longer accessible, as my hearing loss had deteriorated significantly. There was no Message Relay Service in Nova Scotia at that time. At age 46, my hearing loss was so profound that hearing aids were of very little value to me. Then, in December 1998, our support group had a speaker from Dalhousie, and I was able to inquire about the cochlear implant. Through her contact with the Ottawa Civic Hospital, I was sent information, and in February 1999, I underwent various tests which determined that I was a candidate for the procedure. The multichannel cochlear implant is an electronic device developed to restore auditory sensation to the auditory nerve. The stimulation provides a wide range of auditory information needed in recognizing environmental and speech sounds to expand communication ability. I had the operation on May 4, 1999. It was about 6 hours long, and I returned home for one month to heal. On June 7th, I had the activation. A computer chip inside my head is about the size of the tip of a thumb, but not as thick. I wear a speech processor on my belt which is connected by wire to a microphone that is worn on the outside of my head behind my ear. I hear from the side that is implanted; it is so clear that there is no comparison to hearing aids in terms of quality and quantity of sound received. Not all people benefit the same from this procedure. For me, it has been the beginning of a new world of sounds,

some of which I had never heard in my entire life. Thanks to medical technology, I am now again using the regular phone with my family and friends. I can take a more active part in worship at church, hear a clock ticking, communicate with much less stress, watch TV without CC, and hear the birds. I have applied for and obtained new employment. I feel like a different person. I am more relaxed, and my world has been transformed from the darkness of deafness into the light of sound!

Dave Spencer, Nova Scotia

For information on cochlear implants, contact the Ottawa Civic Hospital: phone 1-613-798-5555, ext. 8003; Medical Contacts: Dr. David Schramm, Surgeon and Christiane Sequin, Audiologist

Dear Mailbag,

[Editor's Note: *This "request" was sent to one of ANAC's directors*]

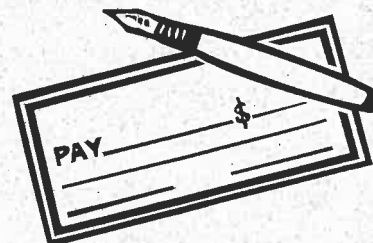
An appeal from a woman in Australia who, about seven years ago, had a tumor the size of a grapefruit removed. The tumor wasn't an acoustic neuroma, but there is some similarity with AN in terms of symptoms following removal (i.e., difficulty in swallowing).

The removal of the tumor generated damage so that she is totally unable to swallow; this has resulted in her requiring a gastronomy [she now has to

blend her food in a blender and feed herself *via* a tube through her umbilicus (belly button)]. The problem is that her supplier of "bulb syringes" has stopped making them [Editor's Note: I understand that the syringe is necessary for her to be able to feed herself.] Anyone who knows of another supplier or an alternative syringe should contact the National Office. The bulb syringe that she has been using is "Contro-Bulb Syringe 60 ml., re-order #DYND20125.

For a Special Occasion!

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



SECOND CANADIAN HEALTH CHARITIES ROUNDTABLE

Trenny Canning (Vice-President) and Glyn Smith (National Coordinator) attended a conference in Ottawa on the weekend of September 18th and 19th. Senior volunteers and staff from small, medium and large national health charities came together to re-affirm their common interests and discuss what mechanism would best suit their needs. The Roundtable had four main objectives: assess progress on work that has been done as a collective since the June 1998 roundtable; determine a mechanism/organizational structure for future work on collective issues; share current information (identify and discuss issues of common concern) and to develop key elements of an agenda for collective action during the next year.

Saturday evening started with a review of the first roundtable and the objectives of the current one. Sunday was spent working in small group sessions and then reporting back to the meeting as a

whole. The small groups looked at three possible organizational structures put forward by the planning committee to launch reflection and discussion about enriching collaboration among all national health charities.

Overwhelming consensus was reached that establishing a coalition of health charities would provide the best avenue for collective action. This alliance would still leave individual organisations with their own identity but would develop a mandate and definition of broad issues common to all. Also identified was the importance of representation from both paid staff and volunteers.

With the decision to move forward, a working group, comprised of representation from paid staff and volunteers from small, medium and large charities, was formed to develop a more in-depth discussion paper.

Our Vice-President, Trenny Canning was invited to serve on the working group in her capacity as a volunteer board member of a small organization. The first meeting of the working group was held in Toronto on November 5th, and was followed by a teleconference on November 23rd. National Organizations can expect to receive a discussion paper for review and input during the early part of December 1999. Anyone wishing to receive a copy of the discussion paper may do so by contacting Trenny anytime after November 29th.

Besides the formal meeting, it gave both Trenny and Glyn the opportunity to meet with other organisations and volunteers and to develop some useful contacts. Financial assistance was provided by Health Canada for travel costs.

Trenny Canning,
tcanning@uwaterloo.ca
Glyn Smith,
anac@compusmart.ab.ca

INFORMATION, EXPERIENCE WITH HEARING AIDS OR IMPLANTS YOUR HELP IS REQUIRED

The Newsletter Committee intends to put together a Connection around the theme of 'hearing'.

Do you or anyone you know have experience with hearing aids or implants (similar to the article presented earlier in this issue from Doug Spencer.) If so, please pass on your comments and thoughts to

Glyn Smith at the National Office. This is also a call to our audiologist and ENT members to forward relevant research papers/editorials to the National Office.

Does lip reading help? Again your comments about this would be welcome, as well as tips that you have learned to help cope with your

deafness or reduced hearing. Contact Glyn at P.O. Box 369, Edmonton, Alberta, T5J 2J6, by telephone at 1-800-561-2622 or by e-mail at: anac@compusmart.ab.ca.

If you have any comments or suggestions on other topics you would like to see addressed in the Connection, let Glyn know.

RESEARCH CALL

Schwannomatosis Study

Drs. Bruce Korf and Gerald Cox of Children's Hospital Boston, are researching the genetic basis of schwannomatosis. They are interested in receiving clinical samples from affected individuals and families whose schwannomatosis is not caused by mutations in the NF2 gene. They are performing genetic linkage and loss of heterozygosity studies to identify these other genetic causes.

From singly affected individuals, the doctors are interested in receiving (1) purified DNA from blood samples or a sample of blood

(5-10 cc in a purple top tube and 3 cc in a green top, sodium heparin tube) and (2) purified DNA from schwannomas or whole tissue from one or more schwannomas (fresh frozen, paraffin embedded etc). From families, they are interested in receiving the same samples as above from both affected and unaffected family members. Also requested is documentation of pathological diagnosis of the tumour and any relevant medical records. The doctors would like to speak directly with interested individuals beforehand to discuss

the research study, answer any questions and review the informed consent form, and make arrangements for shipping and handling of specimens.

Dr. Cox can be contacted at (tel) 617-355-5800 or via e-mail; cox@al.tch.harvard.edu.
Source: Neuro News, Spring 1999.

NF-2 PATIENTS NEEDED for Natural History Studies

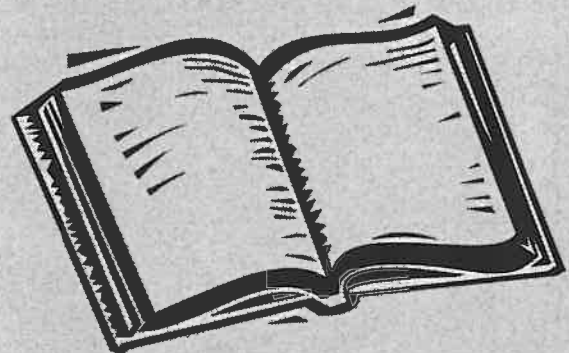
This natural history study will measure the growth rate of vestibular schwannomas in 100 people with NF2, in order to (1) develop predictive factors to determine the normal growth rates for vestibular schwannomas and (2) define all parameters necessary to conduct clinical trials for new therapies for NF2. The study will focus on patients who have been diagnosed with NF2 within the past two years.

The three-year study will be conducted at Massachusetts General Hospital in Boston, the House Ear Institute in Los

Angeles, Mt. Sinai Hospital in New York, and centres in Hamburg, Germany and Manchester, England.

While no new treatments will be part of this study, patients may continue their current treatment during the study. Patients interested in participating should contact

Gloria Yoon, Research Assistant,
The House Ear Institute;
telephone 213-483-4431
or via e-mail;
gyoon@mail.house.hei.org.
Source: Neuro News, Spring 1999



NF2 WEB SITES

Compiled by Glyn Smith, National Coordinator, ANAC.

The following web sites have all been reviewed by the author and were active at the time of review (i.e., October 1999). These sites are provided for information purposes only; ANAC does not endorse any site nor is ANAC responsible for the content of these sites. Also, this list is not exhaustive and I'm sure that there are many more sites available. Comments made directly following the site's address are purely those of the author. Readers are recommended to review each site and make their own decisions.

NF2 CREW
(chat line for NF2 people)
www.webcrossing.com/nf2crew

This web site is prepared by a support group focussed around NF2. Virtually all members either have NF2 or a member of their family does. Membership is world-wide although most of the crew come from the US or Canada. The site provides a list of physicians – mainly from the US but there are a few Canadians. Some physicians also have an e-mail address listed. There is a "real time" chat line (Internet Relay Chat) which happens on Sundays at 1500 hrs and 2030 hrs (eastern). Information is supplied on how to join the chat line - which is free. The site contains a good source of links grouped under headings like, AN/Brain tumours, Closed captioned, Cochlear Implant, Deaf Resources, General Medical Resources, Living with Disabilities, Neurofibromatosis Background, Radiosurgery, Telephone and other Technology.

**NATIONAL
NEUROFIBROMATOSIS
FOUNDATION INC**
www.nf.org

"The NNFF is a partnership of scientists, clinicians, patients and families, chapters volunteers and staff". The site has three main sections - for scientists, for patients and families, and latest developments. There is also a Bulletin Board which is split between NF1 and NF2. Registration is required to access the bulletin board but it is free. There are no links provided and no information about NF other than a section called "What is the difference between NF1 and NF2?". The main content of this site is the bulletin board.

**EUROPEAN FEDERATION FOR
NEUROFIBROMATOSIS
ASSOCIATIONS**
www.nf.org/top/nfeuro.htm

This site provides information about and links to other European NF Associations.

**THE NEUROFIBROMATOSIS
ASSOCIATION**
www.users.zenet.co.uk/neurofibromatosis

This is the web site for the British NF Association. The site contains information about both NF1 and NF2. It also lists publications available through the Association, provides access to recent Association newsletters and has a small number of links to other NF sites.

**NF NETWORK (EUROPEAN
NEUROFIBROMATOSIS
ASSOCIATIONS)**
www.nf-network.huma.org

SMILING



Smiling is infectious,
You catch it like the flu,
When someone smiled at me today,
I started smiling too.

I passed around the corner,
And someone saw my grin,
When he smiled I realised,
I'd passed it on to him.

I thought about that smile,
Then I realised its worth,
A single smile just like mine,
Could travel round the earth.

So, if you feel a smile begin,
Don't leave it undetected,
Let's start an epidemic quick,
And get the world infected.

This site is very similar to the European Federation's site (see above) and has only a small number of links.

**BRITISH COLUMBIA
NEUROFIBROMATOSIS
FOUNDATION**
www.benf.bc.ca

"This site is run by a non-profit charitable organisation serving individuals and families through out British Columbia and Western Canada". There is information about literature available through the organisation and a small number of links. Sections include the latest newsletter, news about NF research in British Columbia, information about NF and details of local support groups in British Columbia.

**NEUROSURGICAL SERVICES -
MASSACHUSETTS GENERAL
HOSPITAL**
<http://neurosurgery.mgh.harvard.edu/ngenethp.htm>

This site contains a good selection of links to other sites. Information is provided about research into NF

taking place at the Massachusetts General Hospital. There is a section of references for health care professionals also available.

JAMA (JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION)

www.ama-assn.org/sci-pubs/journals/archive/jama/vol_278/no-1/rv71001.htm#tab2

This site contains a complete article entitled "The Diagnostic Evaluation and Multidisciplinary Management of Neurofibromatosis 1 and Neurofibromatosis 2".

POEMS ABOUT NF

<http://neurowww2.mgh.harvard.edu/MIND/Poetry/NeurofibromatosisMenu.html>

This is a collection of poems submitted by visitors to the web page.

OTHER NF2 INFORMATION SOURCES

Publications

THE BCNF INFO

(A publication of the British Columbia Neurofibromatosis Foundation).

Ste, 303, 1212 W. Broadway,
Vancouver, BC V6H 3V1
Tel: 604-736-7545
1-800-385-2263
Fax: 604-730-1015
E-mail: bcnf@istar.ca

NEUROFIBROMATOSIS

(a publication of the National Neurofibromatosis Foundation, Inc)

95 Pine Street, 16th Floor, New York,
N.Y. 10005
Tel: 1-800-323-7938 or
212-344-NNFF
E-mail: NNFF@aol.com

NF2 REVIEW

(a publication of The House Ear Institute).

2100 West Third Street, 2nd Floor,
Los Angeles, CA 90057
Tel: 213-484-4431 (voice)
213-484-2642 TDD
Fax: 213-413-0950
E-mail: bgxg89a@prodigy.com

Associations

International Neurofibromatosis
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Kingstone on Thames
K52 6PX, UK



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