

the **CONNECTION**

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ANAC ON THE MOVE

Changes will have occurred at the National Office by the time you read this notice. After two and a half years working with ANAC Nellie Alger, our Administrative Assistant, has decided to move on to other challenges. On behalf of the board and myself I would like to thank Nellie for the hard work she has put in for the Association. We'll miss you Nellie!

Nellie's move has provided the opportunity to evaluate current circumstances and to consider changes. A proposal was put to the board and, after careful consideration, was accepted. As you may know Glyn Smith, the National Coordinator, works for Quandary Solutions, a company that provides

management services for non-profit organizations. It was decided to contract all of the management and staffing of ANAC to Quandary Solutions. This means that Quandary Solutions will supply the National Coordinator as well as the Administrative Assistant. At the same time Quandary Solutions invited ANAC to relocate into their premises (at no cost for rent). This proposal will mean that ANAC can continue to operate at a slightly reduced cost. The telephone number and postal address will stay the same (there will be a new fax number). One big advantage is that there will be someone in the office every day to answer the telephone.

This is an important move for ANAC and its future, as well, its important to remember our past. The old office was located in the Edmonton Ikon/Superior Office building and we would like to thank that organisation for their long support of the organisation. Particular thanks must go to one of our founding members Virginia Garossino who, at the founding of the Association, owned the Superior company.

Please be assured that it will be business as usual for ANAC and, as members, you should not notice any difference in the operation of the Association. If you have further questions don't hesitate to call Glyn Smith at national office.

CHANGES TO THE FORMAT OF THE CONNECTION

You will notice a difference in the format of this copy of the *Connection* due to the current financial situation facing ANAC. We regret having to go to a

'news sheet' format yet it will result in significant savings of about \$1,000 per issue. These savings mean that we can still print three issues this year. In this way the quality of content

remains the same but the presentation becomes less 'professional' than in previous issues. Your comments and feed back is appreciated.

THE FINANCIAL SITUATION

WE have just been notified by Health Canada that they will only supply a \$25,000 grant this year which is for specific projects only. It cannot be used to cover day to day operational expenses. Last year we received \$40,000 which was used for operational funding. The board is looking at ways in which this shortfall can be made up. If you have ideas for funding – particularly if you know of companies or foundations or your employer who may be able to assist us, please contact one of the board members or the national office.

REPORT ON ANNUAL GENERAL MEETING, March 4, 2000

Howard Johnson Harbourside Hotel, Nanaimo,
British Columbia

The Annual General Meeting was held on the Saturday afternoon of the Annual Meeting, which this year was held in Nanaimo. There were 12 members present with sufficient proxy votes to permit a duly constituted Annual General Meeting.

The important items on the agenda were the adoption of the revised bylaws and the appointment of the board. The following people were elected to board positions;

President	Peggy Bray
Treasurer	John Oss
Secretary	Vacant
First Vice President	Michael Klein
Second Vice President	Trenny Canning

The revised bylaws (circulated to all members with the Annual General Meeting information) were adopted with the following amendments;

That the following new item be added to article 4.6.3. of the proposed revised bylaws.

- (a) If a Life Member does not respond to the annual "Renewal of interest in Membership" correspondence within 90 (ninety) days they shall be removed from the active membership list and shall not be entitled to any membership privileges identified under article 4.4

- (b) The Life member may apply to have their membership reinstated at any time within the following 5 (five) years without any further cost to the member."

article 5.1.5. 'Quorum' of the proposed revised bylaws.

That 20% be changed to 15%. The amended article will read "A quorum of the meeting will consist of 15% of the eligible Voting Members present or represented by a proxy"

article 5.2.5. 'Procedure at the Special General Meeting' of the proposed revised bylaws.

That 20% be changed to 15%. The revised article will read "Any Special Meeting has the same method of voting as the Annual General Meeting. A quorum of the meeting shall consist of 15% of the eligible Voting Members present or represented by proxy"

ANNUAL MEETING - DONORS

David & Roslyn Nickel
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AUDITORY BRAINSTEM IMPLANT

Dr Graham Bryce gave a very interesting talk about Auditory Brainstem Implants (ABI) at the Annual meeting. The following notes were taken from his talk and the booklet, Multichannel Auditory Brainstem Implant, 1999, Cochlear Foundation. These remarks not been reviewed by Dr Bryce for accuracy.

There are two types of implants available, ABI and Cochlear Implants. The cochlear implant electrode array is placed in the inner ear of an individual with an intact and functioning auditory nerve. The ABI implant electrode is placed on the surface of the cochlear nucleus in the brainstem, that bypasses

the damaged inner ear and auditory nerve.

Currently the ABI is only available in the USA and is still considered an investigational device. Candidates for ABI have to be diagnosed as Neurofibromatosis Type II and must to have the ABI implanted at the time the tumor is removed. Individuals who have had radiation therapy or gamma knife are not candidates for the implant.

The ABI works by sound being picked up by a small microphone which is located at the ear (it looks like a small behind the ear hearing aid). A cord carries the sound to a speech processor that filters and analyzes the sounds and converts it into coded signals. These signals are sent, by another cord, to the transmitting coil. This coil has a small magnet that holds it in place over the implant. The transmitter sends the coded signals as FM radio signals to the implant which is located

under the skin. This implant then sends the signals to the set of electrodes on the cochlear nucleus in the brainstem. This causes stimulation of the cochlear nucleus, producing responses that can be interpreted by the brain as sound.

The ABI cannot be 'switched on' until some weeks after implanting and usually requires fine tuning over a period of time by an audiologist. The benefits derived from the ABI will vary and also depend on how much the patient perseveres with retraining as the sound generated is very different to 'normal' sound.

Dr Bryce then showed a short video of a young woman with NF2 who had received the ABI and has been successful in adapting to it.

We have just heard that these implants may be possible at other times as well as when the tumor is removed - Editor

ANNUAL MEETING - DONORS

Victoria Chapter

\$200.00

P. F. Bevington and Company CGA Ltd
Certified General Accountant
Box 543,
Campbell River BC V9W 5C1

\$25

Rick & Kathy Pearson (Managers)
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Campbell River, BC V9W 2G6

Door Prize
(3 mirrors)

Evalyn Hyrbko
Member

\$300
Door Prizes

Gift Certificates (Shoppers Drug Mart)

SUMMARY OF THE PRESIDENT'S REPORT TO THE ANNUAL GENERAL MEETING

March 4, 2000

ANAC's mandate has been recharged by the work of our five Working Committees and the staff at the national office in Edmonton.

These committees have broadened the base of volunteer involvement, spread around some of the leadership responsibilities and reorganized the work of the Association. I'll outline some of the achievements made during 1998-99.

1. the Connection Newsletter –the recently-formed editorial committee is coordinated by Trenny Canning. Working with her are Linda Gray, member from AB and former ANAC Office Manager, and Glyn Smith, ANAC National Coordinator. The committee, with assistance from Evalyn Hrybko and Naome Soleil, intends to increase the number of annual issues from two to three.

2. Chapter Development – coordinator Evalyn Hrybko, a director from Vancouver Island, myself and other chapter representatives from across Canada have organized several regional conference calls so local leaders in the West and in the East can speak to each other. We have also initiated an e-mail news

bulletin so local leaders can maintain links between the conference calls. First steps toward the design and development of a Volunteer Resource and Chapter Development Manual are scheduled for this meeting.

3. Info Resource and Dissemination Committee – coordinated by Brenda Ross and Barry Singerman, directors from Toronto, with members Romas Staskevicius of Montreal, Trenny Canning, a director from Kitchener, and Pat Greenwell of Edmonton. Through their persistent efforts the ANAC website was launched last spring and is continually updated to provide patients and interested others with relevant information. Other new educational materials include two booklets, "Hospital Discharge" and "Stereotactic Radiosurgery," and an update of the "Acoustic Neuroma Overview Booklet."

I would also like to mention the many ANAC members who represented us at the Family Physician's International Conference in Victoria in May of last year.

4. Administration Committee – coordinated by Glyn Smith, with Nellie Alder, Office Assistant,

other executive officers and myself. The committee has produced policy manuals describing the responsibilities of each executive position, working committee and staff position. Along with this, office procedures were streamlined to eliminate duplication. The Bylaws have been completely revised and a copy was sent to each of you.

5. Revenue Generation – I coordinate this at the moment, working with Tom Riglar, Vice-President from Vancouver, Michael Klein, a Local Leader from Saskatchewan, Terri Ingham, a member from Niagara Falls, and Glyn Smith. You may recall receiving letters or phone calls this past year. These were all part of this committee's national fundraising campaign. Our efforts raised \$5680 dollars after expenses.

Our members are the backbone of our organization and we currently have a total of 426 members. 157 of these are life memberships, a category we discontinued in 1997 when the costs of operating this benefit became too high. This has been just one of the changes we have made to deal with our limited revenue sources and the decrease in financial support from Health Canada

I wish to take this opportunity to thank Karl Benne, Nancy Laberge and Health Canada for their continued support of ANAC over the years, and specifically for the Transitional Funding Grant of \$50,000 received in March 1999. This grant, coupled with our own fundraising campaign, is providing the financial means to sustain the ongoing work of ANAC over *this* year. However, future funding from Health Canada must be applied to specific projects, not our day-to-day operations. We must depend on our own resources to manage and run the Association on a daily basis.

Sources of revenue to date in 1999.

Health Canada Grants	\$ 50,000
Membership Fees	10,596
Individual Donations	11,901
Corporate Donations	4,000
Fundraising via Chapters	1,024
Promotional Items	4,162
TOTAL	\$ 87,363

I'd like to thank all of the board members, our national coordinator and the others who have contributed to these achievements. As noted, a lot has been accomplished in these last two years and it is due to the efforts of these people. Special thanks go to retiring board members: Naome Soleil from Vancouver, who has been Secretary to the Board; Marie Legault from Montreal, member-at-large and coordinator of local meetings; Lindsey Oss from Toronto, who has also been a member-at-large; Irma Arnold from Wasaga Beach ON, former Director of Stereotactic Radiosurgery, Jackie Diels from Madison, Wisconsin, former Director of Neuromuscular Retraining, and Ruth Harris from Platsville ON, who was Treasurer.

I am looking forward to meeting and working with the new people who fill these positions.

Our focus for the year 2000 + 2001, will be

1. to continue providing patient support through the 1-800 phone line and connecting people together
2. to publish *the Connection* newsletter 3 times per year
3. to maintain and further develop the ANAC website
4. to carry out the annual fund raising plan
5. to develop relationships with new corporate donors
6. to continue our collaborations with other health organizations, such as the Brain Tumor Foundation of Canada; Late Deafened Adult

Support Groups in Halifax and Calgary; NeuroSciences Centre in Hamilton, ON; Brain Injury Groups in Vancouver Island and Edmonton; BC Neurofibromatosis Association; BC Cancer Agency - Stereotactic Radiosurgery Dept; CABTO (Canadian Alliance of Brain Tumor Organizations); CAHC (Canadian Alliance of Health Charities) and others

If the funding assistance from Health Canada is forthcoming, we will be able to complete the following projects:

1. updating and improving our patient database with current information about pre+post treatment symptoms, types of treatment received and other AN experiences in order to link the appropriate people together
2. producing a manual for Volunteer Resource and Chapter Development
3. providing face-to-face training sessions for Local Leaders and others who are interested

I look forward to the continuing enthusiasm and commitments of the ANAC membership as we work together to successfully achieve these objectives.

DEPRESSION AND ACOUSTIC NEUROMA

Evalyn Hrybko and Trenny Caning gave a brief talk about depression and acoustic neuroma at the Annual Meeting in Naniamo.

Evalyn's Talk

Good morning ! Is it a good one for you?

For most of us, some time ago, we began to have an annoying and persistent, yet, faintly minor symptoms in our lives that gradually increased.

For me, it was losing most of the hearing in my left ear, increasing tinnitus, balance problems, increasing unexplained headaches, and later a numbness on my left cheek area. I was 23 years old. My husband and I had a beautiful baby girl. We were busy building our own house. I was frustrated at frequently losing my balance. I remember the day I was painting the ceiling, standing on a makeshift scaffold, and down I came, and then the can of paint. What a mess! Another day I was digging a garden, on a hot day, and then found all of a sudden, I could not walk, I crawled back to the house.

I could go on, you know your story, each of us is different, yet similar. Eventually it is diagnosed, an Acoustic Neuroma tumour. The tumour is address, either by surgery, gamma knife or linac. The family and friends all rally round, bringing cards, flowers, casseroles, etc. Then, eventually you are on you own once again, everyone thinks all is back to normal. But --- you know you are not exactly the same as before. Headaches, lack of directional sounds, loss of hearing, eye irritation, balance problems, and the never ending fatigue. Will I always be like this?

Some find they do not want to go out in public alone – to the bank, to the grocery store. Someone calls your name as you are walking down the mall – where is that voice coming from? If you turn too quickly, you may loose your balance. Sound familiar?

OK! Today is the first day of the journey of the rest of your life. How are you going to deal

with this? Yesterday has come and gone. This AN experience is a "detour" that you never asked for. However, you now have a choice. This "detour", is it going to make you a better person, or a bitter person? Are you going to be self-centered, or, are you going to reach out to others – to learn from, and to share with, to laugh, to cry, to hug? We need to choose to keep on learning, to choose daily that life is good. God is good. My faith in God has been, and is, important to me.

He is my strength.

My mother used to say that as we journey through life, we need to look for the silver lining, it is always there, but at times we need to look for it.

Do you have a bunch of lemons in your life, well then, make lemonade! Your tumour was taken care of, you still have humor, use it, put others at ease.

Maybe if, after what I have said, you still have depression, there could be other physical problems, such as thyroid, or TMJ, maybe something else, look into this. Maybe you are trying to do too much, then you may need to drop or change some activities. I can't play badminton, I can't ski aggressively like my husband, but I have learned to do many other things.

People are special. I have made some wonderful friends through the Acoustic Neuroma Association of Canada. I have learned that by reaching out, and helping others, this is then part of the healing process for me. There is a saying that sometimes in life when things don't go your way, then it is time to adapt, how true. Fifty, sixty years from now when most of us will be gone, what will we be remembered for? I hope for being positive, for caring, for choosing to make our circumstances more pleasant.

In conclusion, I would like to say that kindness is catching, let us do our part to spread it around.

Trenny Canning

Trenny talked about the impact on spouses

and other family members. Sometime people don't understand why you're depressed. A depression counselor will say that it's OK to be depressed – its natural after traumatic events such as the diagnosis and treatment for acoustic neuroma.

Depression is followed by anger. The timing of these stages will vary depending upon the individual. Anger is followed by a mourning stage – mourning for the person that he/she was. Even strong people need help. Help may include antidepressants.

There can be problems if you don't progress through the different stages but stay "stuck" in one stage. Don't feel guilty if you feel depressed.

General Discussion.

Recognize the situation, learn to accept yourself for what you are and who you are. Don't be afraid of taking antidepressants. Recognize that we are all individuals and the impact will be different for different people as well as our individual needs. Strong people may find that family may not recognize that they need help now and the acoustic neuroma person may find it difficult to ask for help.

CANADIAN ALLIANCE OF HEALTH CHARITIES

In 1997, ANAC joined the National Voluntary Health Organizations (NVHO) to assist Health Canada in developing a policy to define the working relationship between Health Canada and volunteer health organizations. Out of this organization we have this year formed the Canadian Alliance of Health Charities or CAHC. It will provide a mechanism and structure for national health charities to work together on common interests and concerns.

Our experiences with NVHO and CAHC have clearly demonstrated the value to us of joining with other organizations who share similar concerns. Together we can act as one

voice that has a greater impact. For this reason we became a founding member of CABTO or The Canadian Alliance of Brain Tumor Organizations. It is an alliance of volunteer organizations dedicated to enhancing the quality of life of brain tumor patients and their families. Its vision is to advocate, both politically and publicly, better patient care and increased government funding for brain tumor research. We seek to accomplish collectively those objectives that could not be accomplished on an individual basis.

GAMMA KNIFE NEWS

In our last edition we reported that the Ministry of Health in Ontario had decided to invest in a Gamma Knife. They had sent a "Request for Proposals" to all Ontario hospitals.

It has now come to our attention the Ministry of Health in Ontario has re thought their position and have decided not to purchase a Gamma Knife.

This means that any Ontario resident who wishes to have Gamma Knife treatment will have to apply to the Ministry's 'Out of Country Treatment' department for funding just as in the rest of the country.

MAKE A DONATION

There are various ways and different occasions that you can use to make a donation to ANAC.

For a birthday, wedding anniversary or other special occasion instead of pondering what to buy make a donation to ANAC instead

Donations can also be made "In Memory of". ANAC will send a special card to the person you indicate.

It's easy to make the donation. Either complete the information on the membership application form – elsewhere in this issue – and send a cheque or pay by Visa - or telephone the National Office at 1-800-561-2622, give us the details and your Visa card number and we will do the rest.

MAILBAG

Thanks For Being There, ANAC

From Linda Gray – former ANAC Office Manager

Dear ANAC,

After spending so many years together with you, ANAC, I am glad I can write to you as an old friend.

Isn't hindsight wonderful? It has certainly shown me how my life has improved thanks to that scary brain tumor surgery I had sixteen years ago...what was it called again - acoustic what?

During my last month at ANAC I sorted through the various files that I have collected since the early years of the Association. You know, the changes are amazing! Creating and developing a base for a successful national non-profit organization means adjust and change, adjust and change, adjust and change. In the beginning we jumped in at the deep end and the learning style was 'hands-on' everything! Now the base is solid and the focus has moved on to the natural next phase, adding more structure.

I still marvel at *me* being a part of such a special undertaking! Thank you, ANAC, for giving me so many opportunities and learning experiences. You are a great teacher. I have learned more than I ever thought I wanted to know. I thought I only wanted to give others the support and information that

was unavailable when I was diagnosed. Instead I guess I wanted to be an Office Manager - I had no idea!

For me, the most important part of my work has always been the conversations with the many, many people who contacted the National Office over the last 15 years. It has been marvellous to watch anxious inquiries change into hesitant volunteers and then become long-lasting friends. It has been interesting to see how each person reacts to their situation - some take what they need and are gone, some stay for many years, some give of themselves for a short time and then reappear later when other commitments are gone. All are remarkable individuals who care and who want to make a difference. They know the importance of passing on to others the help they were given...they all have the positive attitude, optimism, humor, resilience that helps get us through the tough times. I don't know how many times I heard people say 'I am so grateful, so lucky, to only have the problems I have. I could have been much worse off'. Wow, with attitudes like that, the Association can't help but thrive and make a difference.

I have been told by many that they were helped by the information I was able to supply, but I don't know if they realize how much help they also gave to me. By talking to them I was able to understand and work through my own

anger, frustration, depression and impatience...and see the light at the end of the tunnel grow brighter and watch the tunnel shorten. My many, many thanks to all.

Now I am off to follow an interest which has developed because of AN and ANAC. Over the years I have encountered a variety of exercises and therapies that have helped the changes I have experienced in facial weakness, imbalance, memory and concentration. This path led me last year to enrol in holistic health courses at a local Edmonton college. It is a tremendously positive time and each course adds great benefits - I feel like I am in a candy shop! Because we practice the techniques on each other, I have personally benefited by improved facial movement, better balance and learning to relax my 'self'. I can now use these same techniques to help others improve their health and well being. I am meeting new people with that same enthusiasm I found at ANAC!

I am establishing a home-based business and will be offering sessions in the areas of Touch For Health and Reiki, with Hand & Foot Reflexology certification being added later in the year. As I collect and gather materials I will pass along any information which might be beneficial to you and your readers.

With interest I will continue to follow the activities and

development your dedicated volunteers and members have planned for the future of ANAC. They are the 'key' to your existence and to the difference you are making, not only in Canada but around the world.

Keep up the good work and may you be there for many years to come.

With love from,

Linda Gray
477 Knottwood Road West
Edmonton, AB T6K 2V6
ph: (403)463-1635
legray@telusplanet.net

Dear ANAC,

I have had contact with a few patients who are wondering if AN tumors are hereditary. I am not aware of a genetic cause, but there are reports that more than one member in a family have been diagnosed with an acoustic neuroma. If you know of any blood relatives with AN or have read a research study on the subject of AN and heredity, please contact me. I would really like to hear from you.

Evalyn Hrybko
Box 38
Sayward, B.C.
V0P 1R0
(250) 282-3269
ehrybko@oberon.ark.com

Dear Mailbag,

It has been nine years now since I have had the insertion of a gold weight under my eyelid. I want to share that

this has been a big help to me, giving me about 25% more protection from the elements of the air (wind, rain, sunshine, dust and smoke). If you have a wide open eye after surgery, I recommend you check into this procedure for yourself. You would go to your GP and ask to be referred to an ophthalmologist.

In the past two years, I also have had a silicone plug inserted in my lower tear duct (giving 70% more protection) and later one inserted in my upper tear duct (30% more protection). Sometimes we do not know of these available procedures until we read of them in the *Connection*.

If you have questions regarding eye care, you could contact me:

Evalyn Hrybko
Box 38
Sayward, B.C.
V0P 1R0
(250) 282-3269
ehrybko@oberon.ark.com

Remember the Association also publishes a booklet about Eye Care - contact the national office if you would like a free copy - Editor.

PEN PAL WANTED

We have had a request for a Canadian pen pal from an acoustic neuroma patient in Australia. If you are interested in corresponding please contact her directly

Heather Ivezic,
7 Shearer Court,
Mill Park,

Victoria
Australia 3082
Tel 03 9 436 8336.

Heather is a financial administrator who had her surgery in April 2000. Heather has a love of animals and enjoys crafts. She does not have any children.

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

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

GIFTS THAT DON'T COST A CENT

THE GIFT OF LISTENING

But you must really listen. No interrupting, no daydreaming, no planning your response. Just Listen

THE GIFT OF AFFECTION

Be generous with appropriate hugs, kisses, pats on the back and handholds. Let these small actions demonstrate the love you have for family and friends.

HAPPENINGS !

VANCOUVER ISLAND

Victoria

**Contact person –
Rose Christensen –
1-250-598-9693.**

Nov. 15 / 99 a business meeting was held, and ideas shared for a Christmas social.

There were also two guest speakers, Linda Richards, a massage therapist, and Laura Watamachuk, speaking about hearing assistance dogs.

Dec. 4 / 99 Christmas gathering at Rose Christensen's home, seven people present who had a wonderful social time.

March 20 / 2000 A meeting is planned at the Royal Jubilee Hospital, in Victoria. The guest speaker will be Janet Holland, from the Island Deaf and Hard of Hearing Association. This will be a good time for friends and family of hard of hearing people to attend, for tips and information on communicating with hearing impaired people.

The chapter donated \$200 to the Annual Meeting.

Two of our local members have recently had their AN surgeries, Sylvia Anderson, in November, and Beth Smith, in December.

SASKATCHEWAN

Saskatoon,

**Contact person - Doug
McLeay,
1-306-343-9470**

We had our first meeting in November with 16 people present. We have decided to work on a communication strategy with the media, to let others know of our support group.

Another aim of the group is to educate our physicians. We are planning a spring meeting.

Regina

**Contact person,
Michael Klein
1-306-266-2115 e-mail
mklein@sk.sympatico.ca**

Four people met recently and have decided to meet again in April. In this group there is a concern for NF patients, as well as AN patients. One aim we have is to work with health boards to educate the public.

ONTARIO

Hamilton

**Contact Sandra Ireland, 905-
527-4322 ext 4436, e-mail
irelasan@hamcivhos.on.ca**

There is no chapter at this time, but we are hoping to get one started.

Kitchener / Waterloo

**Contact Doug Specht
1-519-886-4436
e-mail dspecht@golden.net**

Doug says the group is up and running, and functioning well!

NOVA SCOTIA

Halifax

**Contact Ed Morrissey at
email
ed.morrissey@ns.sympatico.
ca**

February 15 th, the speaker was a local policeman, talking on "Home Safety", a pertinent topic to us all.

**If there is not a Chapter in
your area then contact the
local contact person (see
listing elsewhere in the
newsletter)**

Evalyn Hrybko

**ANAC
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anac@compusmart.ab.ca
www.anac.ca**

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OFFICE**

LAWRENCE'S STORY

It all began in the summer of 1996 when I was 44 years old. At first my left ear seemed to block, and I also experience a little bit of ringing, so I went to my family doctor. He prescribed some antibiotics as he felt it was just an ear infection. A week later it seemed to have cleared up and the ringing and blocked feeling went away.

Approximately two months later, my ear blocked again, and the doctor gave me a second prescription of antibiotics. Then, a few days later my ear started ringing much louder than the previous time and this symptom has never left me. I was sent for a CAT scan which proved negative. Because the symptoms were continuing, I was referred to a specialist who ordered a few simple tests that showed I had a 75% hearing loss in my left ear.

My wife, Emilie, and I were feeling very frustrated and asked for an MRI. The specialist did not recommend this procedure. We left disappointed as the specialist could not explain a reason for my symptoms, yet he was unwilling to order an MRI. We went back to the specialist in the summer of 1997, and he finally agreed to send me for an MRI.

All this time, I was having bouts of deep depression and having a difficult time handling the ringing in my head. At last, the results came in November 1997. I had an acoustic neuroma. This required another referral to a surgeon in Edmonton, Alberta who explained the surgical procedure. I felt devastated and scared. My surgery was scheduled for February of 1998, but in the meantime, my wife and I did some research and learned about gamma knife treatment

I got in contact with the Acoustic

Neuroma Association of Canada who were very helpful. They promptly sent us a list of people who had surgery as well as those who had gamma knife. This gave us the opportunity to contact both groups of people. Then, I decided that gamma knife was for me.

We spoke to the surgeon, but he did not want to hear about me going to the United States for gamma knife, instead he told me about the modified linear accelerator (LINAC) in Toronto, Ontario. The surgeon said I was on my own if I went for gamma knife, and I understood from the conversation that he would be unwilling to look after me following gamma knife treatment. We were given the impression that patients who went outside Canada for treatment experienced complications, and then it was our medical system that had to deal with the problems. However, I had talked with a lot of patients and refused to be discouraged about my decision.

On February 28, 1998, I had gamma knife treatment done in Rhode Island by Dr George Noren. It was an experience that I will never forget. The hospital staff were very kind and treated me well. The cost for treatment of nearly \$40,000 however was a major financial setback which we had to deal with in the coming months.

Initially Alberta Health Care was unwilling to pay for the out of country gamma knife procedure. The reason seemed to be based on a medical research study funded by the Alberta Heritage Foundation (1998) which compared modified linear accelerator and gamma knife. Although the summary of the study, *Stereotactic Radiosurgery: Options for Albertans* by Wendy L. Schneider and David Hailey confirmed from

other assessments that "there is insufficient information to determine the comparative effectiveness of the GK and the LINAC approaches," the summary also states that "as there is no evidence that there is any difference in effectiveness between GK SRS and LINAC SRS there is no reason to send patients to the USA" (page1).

We found the reasons given by Alberta Health Care for refusing to pay for my treatment were confusing, so we requested an appeal in person. This appeal took approximately six months before we were able to meet, which gave us time to gather further information to support our appeal. Many thanks to all those who helped us in making our appeal a success. After the appeal we were fully reimbursed.

Since then, I have had regular follow up MRI's and, I am glad to say, the tumour is showing the development of necrosis (death of tissue). My hearing has remained the same, and my tinnitus is not as loud as it was prior to treatment. I have had absolutely no side effects from the treatment and feel that gamma knife was the right choice for me. My next MRI is scheduled for February 2000.

Lawrence Gingras
Box 1151
LacLaBiche, Alberta T0A 2C0

Tel: 780-623-7087

Editors note. A copy of the Alberta Heritage Foundation (1998) study referred to above is available from the national office.

MEMBER CONTRIBUTES TO TEXT BOOK

Todd Henkelmann, who is a member of ANAC and Clinical Manager of Eagle Physical Therapy's Facial Rehabilitation Services program, has had a chapter published in a new and prestigious text book. The chapter, entitled A Physical Therapy and Neuromuscular Rehabilitation, is in the new medical text entitled "The Facial Nerve, May's Second Edition" (published by Thieme Medical Publishers of New York) and edited by Mark May MD and Barry Schaitkin MD. Both editors are from the Department of Otolaryngology - Head and Neck Surgery, University of Pittsburgh School of Medicine.

This chapter presents an overview of theory and techniques of facial neuromuscular retraining used to treat facial paralysis (most commonly Bell's palsy). This combines the use of surface EMG biofeedback and mirror exercise, while eschewing the more traditional electrical stimulation method. This method is also used at the University of Pittsburgh's Facial Nerve Centre.

The chapter introduces the use of Polaroid gridfilm photographs as a simple and objective means to document the status of various voluntary facial motions and progress from week to week and month

to month in the clinic.

It also introduces physical therapists to the Sunnybrook Facial Grading System, developed by Brenda Ross and Dr Nedzelski in Toronto, which is used to grade the degree of paralysis and dysfunction present in any facial palsy patient. This easy to administer tool provides a score which is a fraction of 100, and is gaining wide acceptance in the medical community as an objective measurement of progress. It is considered more precise than the more widely used House-Brackmann grading system.

Todd, who specializes in treating both facial palsy and temporomandibular disorder (TMD) patients, treats facial palsy patients exclusively in the Mars clinic, TMD patients in up to five other clinics in North Allegheny and Butler County.

Congratulation Todd.

Editors Note: Brenda Ross (co developer of the Sunnybrook Facial Grading System) is also a member of ANAC.

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Leave a Legacy is a community based effort to encourage people from all walks of life to make gifts to not-for-profit and charitable organizations.

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

Other information can be obtained by visiting the Canadian Association of Gift Planners web site at www.caqp-acpdp.org. If you need further information about leaving ANAC a gift (or are considering it) contact the National Office .

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Information source: The Canadian Association of Gift Planner

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ANAC PRESIDENT TO STEP DOWN

Peggy Bray, who has been President of ANAC for the past three years, plans to step down in the fall. During the past three years Peggy has made a significant contribution to the Association. It is due to her continuous and tireless work that ANAC has continued to progress.

Now the Association needs to look for a replacement for Peggy. At a recent Board meeting it was decided to form a nomination committee to develop a slate for the position of President. The board would like all members to have the opportunity to be involved in this important selection process. Below is a form asking you to suggest the name of a member that you think would be a good candidate for this position. You may wish to volunteer to be considered yourself. The form should be mailed or faxed to the national office to arrive no later than July 30, 2000.

Once all of the suggestions are received at national they will be passed on to the nomination committee. This committee will review the list, contact the people named and develop a slate of appropriate candidates for the position. This slate of candidates will be circulated to all members and a mail in ballot will be carried out.

It is hoped to have the new President elected by the middle of September at the latest.

I wish to suggest the following person for the position of President

_____ (please print)

I believe the above person is a good candidate for the position of President because;

This form must be returned to the National Office by no later than July 30, 2000.
Either mail to P.O. Box 369, Edmonton, Alberta T5J 2J6 or fax to 780-438-4837.

Acoustic Neuroma Association of Canada

Box 369, Edmonton, Alberta T5J 2J6

Phone: 780-428-3384, Fax: 780-425-8519 Email: anac@compusmart.ab.ca, Internet: www.anac.ca

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Your Gift Means We Can

Find it, Treat it, Beat it!

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

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

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

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

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

1. *the Connection* newsletter
2. toll-free patient support telephone line
3. the ANAC website
4. publication and distribution of printed materials
5. public awareness and promotion
6. development of local chapters
7. the purchase of medical items
8. providing memberships for those in need

PLANNED GIVING

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LET'S CONTINUE TO *Find it, Treat it, Beat it!* TOGETHER!

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Please send me:

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- _____ copies of the most recent issue of *the Connection* (newsletter)

Donation for the above materials are gratefully accepted (suggested one dollar per item)