

the Connection

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**Acoustic Neuroma
Association of Canada**

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Neurinomes acoustiques
du Canada**

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1998 ANAC Executive

Peggy Bray, President
Trenny Canning, 2nd Vice-President
Tom Riglar, 3rd Vice-President
Naome Soleil, Secretary
Ruth Harris, Treasurer

*The position of 1st Vice-President is
vacant. Anyone interested in joining the
Board in this capacity should contact
Peggy Bray at 604-708-0266.*

Tinnitus and our Emotions

by Lois N. Cohen, CSW, ACSW, BCD

A tinnitus sufferer raised the question, "Is it alright to feel the way I feel?" It is not only alright, but imperative for our mental health! There are no right or wrong feelings. All of our emotions are real and valid.

Owning and being aware of our feelings enables us to know ourselves – our struggles, fears, joys sorrows, our likes and dislikes, our values and goals. Our emotions enrich our lives.

Sometimes it is too painful to own all of our feelings, especially the negative ones. At these times, we try to deny or stifle them – and we do so at a price. For example, anger turned inward can lead to depression. When we suppress anger, frustration, resentment, hurt, or disappointment, we can feel exhausted and drained, and have little energy left for productive or enjoyable endeavors. Often our ability to concentrate, learn, and work is impaired.

When we suffer from a distressing and potentially debilitating disorder such as tinnitus, it is natural to experience a wide range of negative emotions and to ask, "Why me?" Acknowledging and expressing these feelings enables us to begin to move beyond the devastating impact tinnitus initially has on our lives. The noises can be torturous and interfere with every aspect of our functioning – our work, our leisure, our relationships and our sleep. How can we just take this stride? It's like being invaded by a noisy alien! Many people feel that their lives have been turned upside down, and to feel anything but fury would be unbelievable. We need to, instead, allow

ourselves the adjustment and mourning that is part of our tinnitus experience. It is quite normal to question why it happened and feel the injustice. This is especially understandable when the tinnitus is accompanied by hearing loss which makes one's coping task even more difficult. Mourning the loss of the way we were or the dream of what we thought life would be will enable us to eventually embrace the present and move forward.

When we give ourselves permission to express anger about what happened to us, we begin to accept the reality of our situations. We can constructively express negative feelings in words by using "I feel..." messages. Stating our needs, like "I need to be seated at a quiet table in a restaurant" or asking people to face us when they talk, can help us socialize and follow our interests. Expressing our needs

continued on page 2

Stereotactic Radiosurgery

ANAC will issue an information booklet on stereotactic radiosurgery within the next few months. The booklet will contain educational material on the two forms of stereotactic radiosurgery – Gamma Knife and Linear Accelerator. Funding for the publication of this booklet has been secured. If you can help distribute this booklet within your community, please inform the National office at 403-428-3384 or Irma Arnold at 705-429-2484.

can lead to changes in our environments that can satisfy those needs.

Similarly, when we accept our fears we can begin to look at the thoughts upon which they are based and decide if the thoughts are valid or irrational. This is the cognitive therapy component that helps us resolve the worries and distress that make our noises louder. When we come to terms with a new self-image that accepts limitations and builds on strengths, we build the foundation for functioning fully once again.

In addition to tinnitus' potential to cause anxiety and depression, life's pre-existing stressors can exacerbate our tinnitus. Many tinnitus patients with whom I work struggle with additional difficulties, including marital, family and career problems, infertility, and losses. Although it is tempting to blame our loud noises for all of our suffering and pain, we also need to work on resolving our other dilemmas.



Otherwise, life's unresolved crises will make the tinnitus worse and the vicious cycle will continue.

Our feelings are a gift from our hearts. They act as a barometer and compass to help us know what we need to do for ourselves. When we listen and understand our emotions, we can deal more effectively with them and take the necessary steps to improve our lives. Although we might not be able to control the loudness of our noises, we can control our reaction to them. When we learn to do this we can function more fully in the present while looking more optimistically to the future.

Lois N. Cohen, CWS, ACSW, BCD, is a psychotherapist in Northport, NY who has first-hand experience in learning to integrate tinnitus into her own life. She can be contacted at 516-754-6249.

(Editor's Note: This article was reprinted with permission from the American Tinnitus Association.)

A Personal Experience With Tinnitus

by Evalyn Hrybko

It has been 29 years in June since I had my AN tumor removed. My tinnitus started about 8-10 months before surgery. At that time I remember I had moments, and days, when I felt I just couldn't deal with it any more yet somehow I'd get through each day. I still have tinnitus, but 90% of the time if not more I don't think about it. I've noticed it's worse in the winter months, especially with any changes in the temperature. Also, I've found it especially noticeable when going up and down the ski hill.

By trial and error I've learned to stay away from caffeine, aspirin, and salt. Then the tinnitus is less intense. A head cold always accentuates it. Also, when I'm home alone I really prefer not to have any background noises present (e.g., TV). If I have been traveling the highway or flying, upon reaching my destination it is a big help to lie down with my eyes closed for about 15-20 minutes. That seems to diminish the tinnitus.

On a bad day, I remind myself that it's only on the one side (one ear). My NF2 friends have to deal with being totally deaf and having tinnitus on both sides.

"Living ... Not Surviving"

Adult and Pediatric Brain Tumor Information Day

Presented by the Brain Tumor Foundation of Canada

Saturday
October 24, 1998
Lamplighter Inn
London, Ontario

The 13th Annual Brain Tumor Patient Information Day is a full-day seminar providing an opportunity for people with brain tumors, their families, and friends, together with professionals and interested public, to meet and discuss brain tumors with health care professionals, researchers, and each other.

Inquiries: Brain Tumor Foundation

Tel: (519) 642-7755 or
1-800-265-5106

Fax: (519) 642-7192
or call Pam Del Maestro, Director,
Patient Services
(519) 686-4439

1998 ANAC Annual General Meeting Kitchener- Waterloo, Ontario, CANADA

The day's agenda presented a rare and wonderful opportunity for ANAC members from across Canada to meet in person for the purpose of discussing the business and workings of the Association.

For the Directors, the day began with a full-scale board meeting after which they joined the other members for a tasty and plentiful buffet lunch, catered by the University of Waterloo Food Services. The AGM continued with an interesting speaker, election of officers, reports and informal discussion. It was a time to meet new faces, catch up with old friends, and learn about what makes ANAC tick.

Dr. Lisa Prokopich, Head of the Ocular Department at the University of Waterloo, provided an excellent presentation entitled "Solutions for the Dry Eye ... After the Tears". We learned about the physiology of dry eye and how we can live with it more comfortably. The silicon plug, which blocks one or both tear ducts, seems to be really effective for those who meet the appropriate criteria. Plans are being made to publish an article that more fully describes this treatment.

Congratulations go to the following members who were elected to the Executive: Peggy Bray, President; Trenny Canning, 2nd Vice President; Tom Riglar, 3rd Vice President; Naome Soleil, Secretary; Ruth Harris, Treasurer. The position of 1st Vice President remains vacant; anyone interested in joining the Board in that capacity should contact Peggy Bray at 604-708-0266.

The remainder of the afternoon included introductions of guests and reports from several members.

We were pleased to have Bill Rathborne, President of the Brain Tumor Foundation of Canada join us for the day. He gave valuable information about the



These happy people participated in the ANAC Annual General Meeting on May 30, 1998.

Foundation and encouraged the collaboration of our associations to support the work each other is doing. Like ANAC, the Brain Tumor Foundation, although situated in London, Ontario has local groups across the country.

Many thanks to Karl Benne, representative of Health Canada, for fitting us into his busy schedule. We very much appreciate the interest, support and advice he has shown in the past and continues to give as we work through our various stages of development.

Peggy Bray, who has been acting President since October 1997, presented an interesting and encouraging President's Report. See her remarks in the article titled "President Gives Update at AGM".

Trenny Canning, Co-ordinator of the Newsletter Working Committee, spoke to the changes incorporated in the last issue of *the Connection*. The production and distribution of the newsletter has been ably taken over by the Kitchener/Waterloo Chapter and the University of Waterloo's Graphics Visual Solutions (for typesetting and printing). The new image is part of the positive changes being seen in all areas of ANAC.

Brenda Ross, Co-ordinator of the Information Dissemination Working Committee, told us of ANAC's exciting website project. She hopes the website will be completed by the end of the year. There will be several areas to 'surf', including a special area for members only, and links to other support organizations.

ANAC's Director, Neil Davis from Montreal, reported on the February workshop in Kingston, Ontario, entitled, People, Technology & Practical Solutions,

which he and Trenny Canning attended.

Doug Specht, member of the Kitchener/Waterloo Chapter, shared information and his impressions from the Volunteer Resources & Chapter Development workshop he attended with Evalyn Hrybko and Suzanne Johnston.

Michael Del Grande updated us on his plight to obtain reimbursement from the Ontario government for his choice of treatment, the Gamma Knife. The appeal process is continuing and he continues to hope for a successful outcome.

Two special tributes (reproduced later on in this issue of *the Connection*) were given to George Campbell and Linda Gray.

A special thank you to Dr. Lisa Prokopich for delivering a stimulating and informative presentation, and a big vote of thanks to the University of Waterloo for supplying superior meetings rooms outfitted with the necessary equipment. Thanks also to Trenny Canning, President of the Kitchener/Waterloo Chapter, for arranging and co-ordinating a very successful event; and to Doug Specht, Lucinda Graval and Warren Canning for their help in setting up and supervising various areas during the course of the day. Appreciation and thanks is also expressed to Vincenzo's Fine Foods for designing and subsidizing the gift for the speaker; Cameron's Flower Shop for designing and subsidizing the flower arrangements; and, Dorothy's Flower Market for the buffet table flowers.

Congratulations to the new Executive Board. Thank you for your commitment to ANAC and we look forward to supporting you during your term in office.

Let the new year begin!

President Gives Update at AGM

The Board of Directors has met frequently during the past year. At this time, I would like to report on the work we have undertaken, on your behalf, by presenting an update on the 1997 Annual Report and by highlighting certain points.

I wish to take this opportunity to thank Karl Benne and Health Canada for their continued support of ANAC over the years, and most recently for the Transitional Funding Grants received in August 1997, \$25,000, and March 1998, a grant of \$40,000. These grants, coupled with our own fundraising campaign, provide the financial means to do the re-organization that is critical in charting a sustainable course for ANAC.



As a member of the National Voluntary Health Organizations (NVHO), ANAC has a voice in Health Canada policy development. We are currently engaged in defining the working relationship between Health Canada and volunteer health organizations. ANAC Board Member, Irma Arnold represents us in NVHO dealings to demonstrate the vital importance of federal health grants to ANAC.

As well, we have joined the North American Brain Tumor Coalition, and are in the process of joining the Canadian Congress of Neurological Sciences. We are also investigating ways to work with the Brain Tumor Foundation of Canada. Acoustic neuroma, whether diagnosis, treatment, aftercare or research, relates to the mandates of these organizations. Working together assists ANAC in particular to gain much-needed exposure and understanding, while helping to advance the work of others in brain tumor treatment, research and related government policies.

Last year at this time, ANAC faced both financial and leadership crises. To deal with the immediate financial situation, the Fund Raising Blitz'97 was launched and raised nearly \$25,000. A professional organization and fund developer was hired in June 1997 to conduct a Fund Development and Future Planning Study. This study examined current operations and group organization and structure, identified potential fund-raising opportunities, and conducted in-depth interviews with members.

The three most vital program areas that emerged follow, accompanied by brief descriptions of the actions taken so far.

1. continuation of the Connection newsletter – three issues in 1998 and four issues in 1999

2. establishment and maintenance of chapters so patients and their families can meet to share new medical information and personal experiences – a new Chapter is forming on Vancouver Island while several existing Chapters develop new projects

3. provision of accurate, current and comprehensive information about the treatment options and related outcomes for AN and the strategies used by patients to deal with the consequences of the condition and its treatment – development of an ANAC website and ANAC Hospital Discharge Booklet

One of the key challenges identified was Revenue Generation or Fundraising. The Association cannot, on its own, raise enough money to sustain more than minimal service. This is because the low incidence of AN means relatively few Canadians are affected and the condition is not well known. Therefore, we must rely on our members and those with a direct association with AN for donations. This begins to explain why it is critical to develop and maintain a productive working relationship with Health Canada and other NVHOs.

Another challenge was to recharge ANAC's mandate. We need to broaden the base of volunteer involvement, share some of the leadership responsibilities and reorganize the work of the Association. To achieve this, five Working Committees have been established:

1. Information Resource and Dissemination Committee –

Coordinator, Brenda Ross, a director from Toronto, Ontario

2. the Connection Newsletter Committee

– Coordinator, Trenny Canning, Vice-President

3. Administration Committee – consisting of Linda Gray, myself and some of the newly elected executive officers

4. Revenue Generation Committee

– Tom Riglar, Vice President, and myself. This area is in real need of leadership. We have some ideas for fundraising, however we need someone who can take these, add more, develop a strategy and put it into action. ANAC has grown up since its inception in 1983 as a support organization. Now we must continue that support and develop ways to become more financially self-sustaining. Look to yourself or someone you know who could champion this effort.

5. Chapter Development – Evalyn

Hrybko, a director from Vancouver Island, coordinates this committee and has talked

personally with chapters across Canada. Communication seems to come up again and again in terms of learning from each other within chapters and from other chapters across Canada. A first step toward this would be to set up regional conference calls so that local leaders in the West and in the East can speak to each other.

I'd like to add a few comments about the financial side of Chapter Development. Chapters have been asked to raise money to cover their own expenses for postage, photocopies, room rental, flowers, telephone, and so on. In this way, chapters contribute to our head office by freeing staff to deal with other pressing matters, as well as becoming more autonomous in their own right. And certainly, if chapter groups can donate any additional monies to the National Association after their own expenses are covered, it would be much appreciated.

Finally, I'd like to wrap up my remarks by indicating the areas that we want to concentrate on in the next year:

- information dissemination through the Connection newsletter, the ANAC website, the development of a volunteer manual, and updating ANAC literature
- a national fundraising campaign that will result in a commitment from ANAC membership to donate generously each year
- chapter development, where more people are in direct communication with each other
- attendance at national medical conferences to raise awareness of AN and thus promote earlier diagnosis and treatment
- support the right of Canadians to have all treatment options available in Canada. Microsurgery, monitoring and linear accelerator (a form of stereotactic radiosurgery) are available. However, stereotactic radiosurgery, in the form of the Gamma Knife, is not. It is becoming almost impossible for Canadians to access it.

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



Mailbag

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

Dear ANAC:

My name is Carolyn Walker and I live in Courtenay, B.C. In October 1996 I was diagnosed with Bell's Palsy which devastated me. My recovery has been very slow but I am very hopeful that it will be complete; however, as time goes by, there is always that doubt as to whether I will recover completely or not. I have always tried to maintain a positive attitude and have never 'hid behind closed doors'. I have always been optimistic and believed that if I should not recover completely, then life goes on and only I can change it. Therefore, I continued all my activities very soon after I was diagnosed even though I knew I looked different. It took a lot of courage to go out in public and go back to work. People would look at me and feel sorry for me. What I did find out was that there was a wonderful network of associates, friends and people out there that were very supportive and encouraged me many times, especially when I was feeling down. If I had stayed home I would never have experienced that network.

I first heard of ANAC soon after I was diagnosed from a friend of a friend, Ann Rae, who is a member of your Association. I contacted the Association for literature on Bell's Palsy and to purchase some

Guibor bandages. ANAC was helpful and sent me all the information it had along with the bandages. I had every intention of joining at that time, however, I returned to work and found out that I did not have the energy to get involved. My plan was to retire at the end of December 1997 and I would attend a meeting then. In September 1997, I started dancing in the same class as Ann Rae and she encouraged me to attend the meetings and kept me informed as to when and where they would be held.

May 8, 1998 was the first meeting I attended; I am very happy that I did! There were nine members present and I came away feeling that I WAS NOT ALONE and was very interested in hearing about techniques and procedures for problems such as dry eye. I also came away knowing that I had eight other friends to call on.

My plan is to continue to attend these meetings and perhaps assist in getting information out to the public about the Association as I believe that a support group is so important for one's recovery in any illness.

Carolyn Walker
P.O. Box 1008, Royston, B.C., V0R 2V0
250-335-0633

Dear ANAC:

I was diagnosed with AN in late August, 1997 and had surgery to remove the tumor on Sept 12. I was very fortunate that they did not have to cut any of the nerves in order to remove the tumor. My hearing in my left ear, the side where my tumor was, is not great, but my biggest problem is my headaches. I have not gone a day in 8 months without a headache, and some of them are really excruciating. My neck seems to be stiff a lot as well, so I've been going to massage therapy and doing neck stretches. I have been told, and I realize, that I am very lucky that this is all I have to deal with. Sometimes that line gets a bit tiresome. I feel quite depressed sometimes as it is very wearing to experience headaches every day and I was not a 'headachy' person to start with. I used to be a very active person and now can only walk at a leisurely pace.

Being that ANAC is made of people who have gone through this, could you share with me any incites? Will I eventually go through a day without a headache, or feel normal again? Is there anything to take besides Tylenol, as I realize taking these every day for an extended period of time is not good. I am off work again because my headaches are getting worse, but now I have it down to two Tylenol a day and an

anti-inflammatory at night (Surgam).

I now realize it may be a while before my headaches disappear – if ever. I'd like to resume jogging and I am still looking for alternative medicines to alleviate the headaches. I have also gone back to work again – a Phys.Ed. teacher in an Elementary School. Thank you for your time and patience.

Jill MacDonald
23 Brousseau St., Bromont, QC J2L 1W7

Dear ANAC:

Thanks for the AGM information. I will not be attending but I am returning a signed proxy into capable hands. I am always excited to receive mail from ANAC where I can read about the life of the Association and all the good things that come from it. I must admit I am not an active chapter member, and I have not yet attended a local meeting, but I sincerely appreciate receiving the Connection.

I am an AN survivor. 1995 was the Year of Years! My years as an Elementary School Principal (since 1982) came to an end in June, my 60th birthday arrived in August and AN surgery entered my presence in September. I first learned about my tumor in July 1993 but little was available to read. On a visit to the ENT Clinic in Halifax I was introduced to the Connection and it has since been my source of information and strength. The medical articles and personal testimonies of AN members were heart rendering but encouraging at the same time. I have kept every copy I was given or received from the Association and often re-read the articles and notes.

I endeavor to live each day with a positive attitude and thank God for the strength He has given to me to walk this walk. I sometimes wonder what lies ahead, and because no one can tell me, I ask God to take my hand and lead me and walk with me.

I am enclosing a cheque for membership and donation. As stated my proxy is also enclosed along with every good wish for a successful ANAC Annual Meeting to all in attendance.

Like all AN people, I sometimes get down in spirits and I would enjoy corresponding with someone. Best wishes to all.

Shirley Sears
260 Glenoid Dr., Truro, NS BAN 1P9

Dear Peggy Bray:

Thank goodness we have people like you and Ruth Harris who are talented and dedicated enough to run our Association for the members. I want to thank you and Ruth for all the work that has been done.

Good luck at the AGM on May 30/98. I cannot attend, so I have enclosed my

proxy form, signed and dated.

Also please find enclosed my cheque to add to the grant from Health Canada. I still like to help a little each year.

Merton Brown
362 Uplands Drive, Kelowna, BC
V1W 4S6

ANAC Participated in Conferences

Chapter Development, Barrie, Ontario, March 27-March 29 1998 – Doug Specht, Kitchener/Waterloo Chapter

I spent the weekend at the Kempenfelt Conference Centre in Barrie, Ontario, along with Evalyn Hrybko (Sayward, B.C.) and Suzanne Johnston (Toronto, ON), and about 50 representatives from various other organizations, including the Canadian Celiac Association, the Huntington Society of Canada, ALS Society, Crohn's and Colitis Foundation. The conference, funded by the Health Canada, was very thought-provoking and inspiring. It was aimed primarily at small organizations. I would estimate that ANAC was one of the smallest groups present. The conference was extremely well organized and packed with sessions. Topics for the various sessions included, chapter development, volunteer training, expectations of the volunteer and the organization, fund raising, and coping with change. During the workshop portion of the conference, change in every aspect of an organization was a common problem; from funding...to purpose...to volunteer screening...to chapter/organization and direction. The conference provided me with the opportunity to meet other members of ANAC and to participate in working on a strategy to promote ANAC further.

People, Technology and Practical Solutions, Kingston, Ontario, February 14-15, 1998 – Neil Davis, Director, Montreal

The People, Technology, and Practical Solutions Workshop in Kingston, Ontario in February allowed Trenny Canning and me to meet with members of other National Voluntary Health Organizations (NVHOs) and discuss issues which affect all such organizations. One of the key issues highlighted again and again was the fact that although technology is wonderful, organizations must have on-going, regular access to the expertise. Expertise is necessary to take advantage of technology (e.g., create and maintain web sites) and to ensure that they are able to handle the anticipated increase in, for example, requests for information. Much was learned at this enjoyable conference and ANAC will surely benefit from the helpful ideas that our peers provided. We hope we were able to help them as well.

Framing a New Relationship Between National Voluntary Organizations Working in Health and Health Canada – Toronto, Ontario, June 29, 1998 – Trenny Canning, Vice-President

In June 1998, I represented ANAC at a conference on improving the relationship between Health Canada and National Voluntary Organizations Working in Health. This relationship was brought to the fore on March 31, 1997, when Health Canada eliminated the core funding grants to National Voluntary Health Organizations, including ANAC. A Joint Working Group was established to explore options for new partnerships, not only with NVHOs but with all national voluntary sector organizations working in health. Core operating support to selected groups was identified as one of the issues the group would address. A policy framework document has been prepared and circulated to NVHOs to obtain their feedback; hence the purpose of the conference. The framework document encompasses purpose and expectations, explicit recognition, creating a solid relationship, defining the financial relationship, contributing roles in policy development, accountability and "next steps". On a more personal note, I found it encouraging that Health Canada is seeking input on the policy framework from the major stakeholders. The policy framework will have a profound effect on organizations like ANAC. When finalized, copies of the framework will be made available to members upon request or, depending on its size, reprinted in a future issue of the Connection.

President's Corner

1998 has already been a year with many highlights. The ANAC Annual General Meeting in Kitchener provided a wonderful opportunity for me to meet with members and directors face to face, often for the first time. I had communicated with many of these people by telephone and e-mail, so to actually meet them personally was fun. To feel our connections grow and become strengthened was meaningful to me, and I believe of value to the Association as a whole.

I am also excited by the news of different Chapter activities and initiatives across Canada. Vancouver Island is in the process of establishing a second Chapter. Vancouver has launched their own fundraising efforts with a letter campaign and the placement of donation cans in 21 Liquor Control Board Stores for one month. Montreal has been running announcements on three different radio stations to alert the public to the symptoms of acoustic neuroma and to the support and information provided by ANAC. Members from the Toronto Chapter plus others are developing an ANAC website that they intend to have operational by this fall. The Kitchener-Waterloo Chapter held a very successful garage sale that received coverage in their local newspaper, which in turn produced much-needed exposure for ANAC. Halifax continues to hold regular support and information meetings as the AN and Late Deafened Adult Support Group.

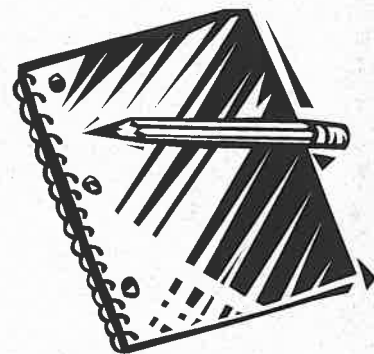
Our organization is also facing some challenges. Linda Gray, one of the founders of ANAC and our key staff person, will leave her official position by the end of the summer to pursue work in other health-related areas. She has been the fount of information and behind-the-scenes worker that the Association has depended on since 1983. Her move will be difficult



for us all, but our appreciation and connection with Linda will continue as she finds other ways to care for people during their healing process. At present, the National Coordinator is a part-time position located in Edmonton. If you or someone you know is skilled in office management and who has a commitment to ANAC would like to apply, please contact Peter Irwin, Human Resource Specialist at 403-892-2727 or email pirwin@compusmart.ab.ca.

Another challenge, of a more ongoing nature, is that of revenue generation or fundraising. Please don't let yourself be misled into thinking that the recent grants from Health Canada end our financial problems and responsibilities. Those grants are transitional and are only intended to assist us to develop alternative resources. Chapters that are creating ways to raise the funds necessary to cover their own expenses are to be congratulated. The design and implementation of a national fundraising campaign is critical. ANAC has grown since its inception as a support organization, and now we must continue to offer support while developing ways to become more financially self-sustaining. This area is in real need of leadership. We have some ideas, and we need someone who will take these ideas, add others, and put the whole thing into action. Are you this someone?

Peggy Bray



The Acoustic Neuroma Association of Canada, a voluntary health organization, has a challenging part-time opportunity for a: NATIONAL COORDINATOR

The successful candidate will provide mgmt; admin and fund raising expertise to the membership, board of directors & medical community.

Duties: program development, meeting coordination, support working committees, finance & admin. services, & patient support. You will have related post-sec educ & several years experience in the non-profit sector. You have proven skills in association & volunteer mgmt., are well organized and an effective communicator. State your salary expectations and apply to:

HUMAN RESOURCE PARTNERS,
9736-101A Str, Edm, AB T5K 2R6.
Call 892-2727 for info.



H a p p e n i n g s !

Ideas for Leaders of Local Chapters

— Evalyn Hrybko, Sayward, B.C.

Meetings

- develop and circulate a questionnaire on what is wanted at local meetings
- encourage and welcome family members to attend
- keep meetings simple: plan for a 20-30 min. program, leave time for eating (good way to get people mixing) and for socializing
- advertise the meetings on local radio and TV stations, newspaper
- notify individuals on mailing list 3-4 weeks in advance by telephone and/or mail
- where to meet: someone's home, restaurant with quiet area, a church, university, school
- name tags are helpful
- it's OK when people come to several meetings and then choose not to come again; not everyone is a meeting person (perhaps they are ready to get on with their life again — that's healthy and healing)

Speakers

- invite speakers from organizations with similar interests: NF, AboutFace, Bell's Palsy, Stroke, Hard of Hearing
- other topic and speaker suggestions: hearing-related, speech therapy, eye care, balance, reconstructive surgery, various exercise/fitness regimes (spas, Tai Chi, golf, water, community colleges, martial arts, etc.), psychology, humor, positive-thinking, complimentary therapies (massage, acupressure, chiropractor, etc.), pharmacy, corporations
- develop a poster on AN and ANAC to display on local bulletin boards (malls, schools, health centers, businesses, etc.)
- invite the local members to speak about their profession, business or work
- tape the speakers so their talks can be printed in *the Connection*

Chapter Structure

- don't be concerned if everything you want for your chapter does not succeed, be content with small and ongoing successes
- be willing to spread and share the workload
- remember: change does not mean failure, sometimes change means growth
- not every chapter/area has people willing to be leaders; don't panic — chapters take time to develop; someone will come forward in the future
- all volunteer positions are important — utilize people's skills, expertise and preferences: some people like to fundraise, to chair meetings, to bring baking, to telephone, write letters — encourage each one and create a team or family

Leadership

- commit to a set number of years as leader, i.e., two to three years is average
- within your term, teach and encourage others to replace you
- sometimes the leader will need to diffuse tension and at the same time realize everyone's opinion has merit
- encourage and welcome family members as well as AN people to become leaders
- tap into the willing attitudes of local members

Other events

- investigate the possibility of a "mini" conference for your area: invite leaders from other health-related, non-profit organizations to join together for an event (i.e., one day or evening); share ideas with each other

In conclusion, each and every chapter will be different from the others because it will reflect the personalities of its members; be creative and enjoy yourselves!



Kitchener/Waterloo, Ontario

The Kitchener/Waterloo Chapter hosted the ANAC Annual General Meeting in May of 1998; this event kept us occupied and out of trouble for a while! My thanks to all the members of the K/W Chapter and National for their help in making the meeting a success. (Mom, thanks for watching your grandchildren; and Warren, thanks for doing everything I asked!)

On June 14, 1998, the K/W Chapter organized and held a garage sale with all proceeds going to the ANAC (a portion to the National Office and a portion to the K/W Chapter); we raised more than \$1,000 and received significant publicity in the local newspaper (complete with a photo of me and some garage sale items!). Not only was the garage sale a success in the amount of money it raised, but it also resulted in my receiving telephone calls and meeting personally (at the garage sale), individuals who had/have an acoustic neuroma and were unaware of the existence of the National Office, let alone the K/W Chapter. All of the items that did not sell were donated to other organizations that help those in need.

On June 17th, the K/W Chapter held a meeting to discuss a number of issues, including the success of the garage sale,

and developed a number of initiatives to make our group more visible and effective (like opening up a bank account!).

Trenny Canning, President
K/W Chapter
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Vancouver Island, British Columbia

Friday, May 8, 1998 – Comox. Nine people attended an informal luncheon gathering. We were pleased to welcome a person with Bell's Palsy.

Saturday, June 6, 1998 – Nanaimo. 19 people attended and 10 were first-timers. I spoke about the Chapter Development workshop I attended in March 1998 in Barrie, Ontario. Sally Doney shared her experiences with AN and gamma knife treatment (just over one year ago) and showed photographs of her experience. This was helpful and we had a good discussion regarding gamma knife.

Saturday, May 30, 1998 – Victoria. 14 individuals attended, three for the first time. I shared my experiences from the workshop on Chapter Development and Sally Doney shared her gamma knife treatment experience. Rose Christensen brought her trained hearing dog, Cleo, and told of how invaluable her dog is to her.

At the meeting, Harry Kraeker announced that he would no longer be contact person for the Vancouver Island chapter. We would like to express our thanks to Harry for starting our group off and keeping it going for three years. It is to his credit that it is taking four people to replace him. Rose Christensen, Linda Main, Rosemary Higgs and Susan Rankin will meet in August and set the direction for the chapter. Any other members who wish to be a part of this committee are welcome to contact any one of us. Although we will be working together each of us has agreed to take on an area of responsibility: Rose will coordinate meetings, Linda agreed to be our contact person and has had both microsurgery and stereotactic radiosurgery,

Rosemary Higgs will be our scribe and Susan Rankin will continue as treasurer and back-up contact person. Our phone numbers are: Rose Christensen (250)598-9693, Linda Main (250)642-7249, Rosemary Higgs (250)656-0675, Susan Rankin (250)595-0440.

At these meetings, a variety of AN literature was available. Many people have commented on how practical the bookmarks are to pass on to the medical profession. These gatherings are beneficial not only to AN people but also to family members and to people with other cranial tumors, as well as people who have had Bell's Palsy.

Evalyn Hrybko
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Acoustic Neuroma and Late Deafened Adult Support Group, Nova Scotia

Our group began at the urging of Anna Parkinson in July 1991, a few months after my first operation. A meeting was called and the group met at one of the local hospitals. We now meet at the social room of an apartment building of one of the members. It was agreed that we would hold monthly meetings except during the summer months. There have been some meetings that we have had to cancel, due to poor weather or the absence of a key person, speaker.

Our group includes AN, deaf, either from NF2, or hereditary deafness. We purchased some equipment – first a lap top computer, then a panel and an overhead projector. We try to have speakers at most meetings. These range from doctors directly connected to AN, audiologists, physiotherapists, stress management experts and members themselves. There is always a question period, followed by coffee and tea (and sweets). Each month, a copy of our newsletter gets sent to members (and National). We currently have about 40 members, with dues at \$20.00 per year (for those who can afford it). One important function of our group is to

remember those who are sick. We send a card and some flowers in an AN mug.

Ed Morrissey
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Edmonton Chapter News

We are sorry to report that in February of this year, due to personal reasons and commitments, Verna Thoman and Anna Krauthahn resigned from the Edmonton Chapter executive. They have spent many volunteer hours helping local AN members and new inquiries through telephone conversations, arranging meetings, and hosting social gatherings. Verna and Anna, we wish you well in your present activities, and we appreciate that you are continuing to be involved locally, on a more informal level, as your time and commitments permit.

Volunteers who are interested in filling or learning more about the positions of President and Secretary for the Edmonton area, please contact Evalyn Hrybko, Chairperson of the Chapter Development Working Committee. She can be reached by calling 250-282-3269 or writing: Box 38 Sayward, BC V0P 1R0.

Also, a contact person is needed for Alberta. The position provides support, information and assistance to inquiries and people with symptoms of AN. It is a very rewarding and learning experience and supports a win-win situation. Anyone interested contact Evalyn Hrybko (see above address).

Glen Sustrik, Linda Gray and Susan McCulloch participated in the Great Human Race in April, raising over \$250 for the Edmonton Chapter activities. Someone is needed to organize and expand this campaign in the coming year...the commitment is seasonal and short term. Anyone interested in 'running' the Race, please contact Linda Gray @ 403-463-1635 for more details.

Have a great summer!
Linda Gray

Software Aids Communication for the Deaf

(Editor's Note: The following article was published in the NF2 Review and is reprinted, with permission, in the Connection.)



Adjusting to NF2 is not an easy task. Staying 'adjusted' is a task which never seems to end. During my early adjustment period, a therapist asked what would make me happy. I replied if I could have everything back! She said that was not possible and then I could not think of a reply for her. However, I did think about the question over the next few weeks.

Perhaps reading a good book would make me happy? The book I chose to read was Emily Brontë's *Wuthering Heights*. I'm not exactly a literary scholar so it came as a surprise that I thought it was a beautiful novel. *Wuthering Heights* was about two families who lived in neighbouring ranches on the English Yorkshire moors during the 18th century. *Wuthering Heights* was about a lot of things but what stood out to me was the isolation. I may not have known it at the time but the isolation in *Wuthering Heights* was similar to the new found isolation I was trying to deal with. Nobody was deaf or had NF2 in *Wuthering Heights* but the time period, the remote, distant and harsh setting created much isolation. One would rarely venture further than the neighbouring ranch. On a snowy winter night, one was often afraid of even leaving home for fear of becoming lost.

Things have changed much since the 18th century and most of the isolation associated with *Wuthering Heights* has disappeared. Travel is much easier and we have many more luxuries. New items constantly appear to help us in our daily lives. In the past decade, computers have made a huge impact in almost all aspects of our lives. Recently, IBM has developed a voice recognition product called 'VoiceType'. As the name may imply, VoiceType allows you to talk to the computer and have your words appear typed on the computer screen. VoiceType was developed for hearing users who would rather talk to their computer than type. VoiceType could potentially be an extremely valuable tool for the deaf community. When you can't lip-read someone (which occurs often), just ask them to speak to your computer! We recently purchased VoiceType at work to help improve communication between me and my co-workers. I'd like to share with you some experiences in trying to adapt VoiceType to a deaf world.

VoiceType generally types speech very well once the user becomes familiar with 'isolated speech'. Isolated speech is pronouncing all the syllables in each word and not slurring words together (isolated speech would also make lip-reading much easier). VoiceType not only performs typing but allows the user to manage their desktop with speech, eliminating essentially all typing or mouse clicks. I think most computer users would enjoy using VoiceType. It's simple to use, integrates nicely with other computer software and works on a standard computer (computer requirements are: a P100 with 16 MB RAM minimum, a sound card and Windows 95). I was surprised with VoiceType's accuracy and large vocabulary of everyday and technical words.

Currently, I think there are a number of limitations that prevent VoiceType from being a major breakthrough as a communication tool for the deaf. Meeting or group situations could potentially be the area where VoiceType would be most valuable to deaf people. However, VoiceType does not work well in these situations. VoiceType's microphone must be positioned close to the speaker's lips and any 'cross-talk' in the meeting produces gibberish on the computer screen.

I found people are quick to learn isolated speech but often find using it awkward (like continuously talking in a monotone). I also found people generally feel awkward talking to a computer. I think this and using isolated speech would be more acceptable if the use of VoiceType became more widespread. VoiceType has worked best for me in one-on-one situations where the other person has a lot of talking to do. However, these situations are not common.

Lip-reading and writing notes is still preferred for short, interactive conversations. IBM has a 'home version' of VoiceType called *Simply Speaking* at a much reduced price. I would expect VoiceType may work better at home because there are fewer voices and longer conversations. Despite the drawbacks for the deaf user, I think VoiceType is a significant development that will likely have a major role as computers continue to evolve. Hopefully, VoiceType will continue to improve to the point where deaf users can read someone's speech like reading a book!

Frank Fusca, NF2 Contact
email: ffusca@onramp.ca

Honorary Member

ANAC has had the pleasure of working with a number of individuals who have "made a difference;" and whose involvement with the organization has helped it become what it is today. The Board of Directors wants to recognize these individuals for their dedication and commitment to ANAC. In the Winter of 1998, the Board approved the establishment of the title, Honorary Member of the Acoustic Neuroma Association of Canada, to be awarded to individuals who have contributed distinctive and distinguished service to the Association. Criteria have now been established and are reprinted below. Nominations may be made by any member of the Association.

I. Honorary Member of the Acoustic Neuroma Association of Canada

ANAC has established a category called "Honorary Member of the Acoustic Neuroma Association of Canada (ANAC)." Honorary membership may be bestowed upon individuals who have contributed distinctive and distinguished service to the Association, which means those who have contributed "above and beyond" that expected of them in their role(s) with the Association.

II. Eligibility

The honour may be bestowed upon anyone, including members of the Association, members of the Board of Directors, members of the Medical Advisory Board and others.

Note: Members of the Board of Directors or Medical Advisory Board should only be honoured upon their retirement or completion of service.

III. Nomination Process

All nominations for "Honorary Member of the Acoustic Neuroma Association of Canada" will be considered by the Board of Directors. The Board will then recommend to the President that the individual(s) be awarded the title "Honorary Member of the Acoustic Neuroma Association of Canada".

All nominations must be made in writing and should include a statement by the nominator(s), outlining in detail the reasons why they feel the nomination should be considered. Supporting documentation should be provided when possible.

The Board of Directors will be responsible not only for screening and vetting the nominations, but for soliciting nominations and thereby ensuring that deserving individuals are not overlooked.

V. Rights of Award Holders

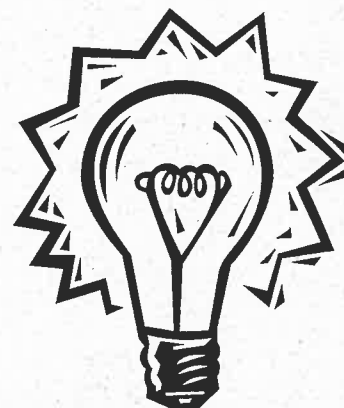
There are no obligations on the part of the award holder or the Association. There will be a section in *the Connection* describing the award and listing those individuals who have received it. Although Honorary Members are not required to submit an annual membership fee, regular donations are encouraged.

VI. Presenting the Award

The investiture ceremony will consist of a letter and certificate from the President, with a notation in a subsequent newsletter.

Innovative Fundraising Ideas

Safeway, Shoppers Drug Mart, and Fields Department Stores in Campbell River, Vancouver Island, BC have agreed to provide Evalyn Hrybko with a gift certificate to be spent in their stores in exchange for a large amount of sales slips. She will forward a personal cheque to ANAC for the amount of the gift certificate. Please send her your sales slips for redemption and suggest a similar proposal to stores in your community.



*Evalyn Hrybko's address is:
Box 38
Sayward, BC
B0P 1R0*

Tributes

George Campbell

This Tribute is to one of ANAC's Founders, George Campbell.

George Walter Campbell died at the age of 85 years on May 1, 1998. He is survived by his loving wife Velma and their married children and grandchildren.

George, a native Edmontonian, was active in local charities like the Edmonton Symphony Orchestra, the Anglican Church, and also in the Edmonton business community.

His commitment to ANAC began when his wife, Velma was diagnosed with a recurrence of acoustic neuroma in early 1983. With this second surgery Velma encountered facial paralysis and balance problems that she had not experienced before, and her recovery was difficult.

Shortly after Velma's surgery, we met through our physiotherapist and later I introduced her to Virginia Garossino. George and Virginia's husband Dick helped the three of us establish ANAC. Although he was a man behind the scenes, George played a key role in the development of the Association through his financial commitment, among other things. His business contacts brought us the legal counsel, a logo, and several corporate donors, all of which remain today.

My most vivid memory of George is in that first year, 1983 when the five of us met. We had just learned of an American ANA Symposium in Nashville and George urged Velma to attend. Because she was still troubled by balance and eye problems, and he was unable to attend, he made it possible for me to accompany her. Nashville was the last place I wanted to go, yet Velma needed assistance and I'm glad I went. That weekend influenced the dedication we have given to ANAC over the years. We learned the importance of networking, sharing, educating ourselves, finding humor in our situation, and knowing we never wanted anyone else to go through this experience alone as we had.

It is important to remember that we all choose our own way of helping others and we never know where or how far that help goes. ANAC is a good example of what happens when just a few people, like the five who started this organization, join forces – we did not know what we could offer but the will was there. We made a difference, and the Association is still making a difference.

Throughout their active lives George and Velma made volunteering a priority, and many people and causes have been helped by their work.

Linda Gray, May 30, 1998

Linda Gray

Linda Gray will soon be leaving us.

For 15 years, she has been the heart of ANAC. Her voice was the sympathetic one that offered dependable and accurate information to people who were dealing with all aspects of acoustic neuroma before and after treatment. Her shoulder was the one to lean on for family members as they waited out the long hours of surgery undergone by a loved one. She has been the connection between the individual members, newly diagnosed patients, the medical community and the corporate world, and helped turned ANAC into a cohesive national association.

We've come to depend on Linda for many things over these years, and we are all going to miss her and her fine qualities. It is her kind heart and her sense of humor that I will miss most. She is taking all of these qualities with her as she moves into her new career as a practitioner of Touch for Health – an appropriate field for someone like Linda – and we wish her the very best.

Linda was one of the founders of ANAC, and received recognition for this at the Toronto Symposium in 1993. More recently, she was presented with a small gift at this year's AGM. These things only just begin to thank her for the many efforts she has willingly contributed. If you are one of those who would like to offer their own thanks and recognition to Linda, you can make a donation to ANAC in tribute to her.

Peggy Bray, May 30, 1998

It's never too early to start thinking about Christmas (or birthdays)!

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



Special Thanks to our Contributors December 1/97 to May 31/98*

A BIG THANK YOU to all those listed below for sharing in this helpful way. Contributions are tax deductible and are promptly acknowledged with an appropriate card or letter; gift amounts are not disclosed.

The Board of Directors of ANAC wants to recognize those people who make annual extraordinary contributions by establishing the following categories: Bronze Circle (\$300 - \$499); Silver Circle (\$500 - \$999); Gold Circle (\$1000 or more). Look to the next issue of *the Connection* for recognition of these new categories.

**If you have contributed to or joined the Association since May 31, 1998, your contribution will be recognized in the next issue of the Connection.*

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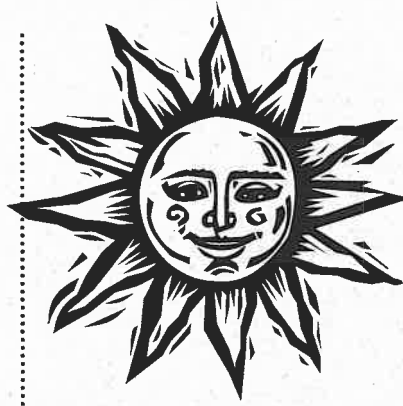
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