

the Connection

Published Quarterly by the Acoustic Neuroma Association of Canada

Canadian Publications Mail
Agreement #106178
Charitable Registration #0677682-11

Vol. 9 Issue 2 July 15, 1996

Positive Thinking

PLEASE DO NOT
REMOVE

by Mr. George Krupinski

Mr. Krupinski was a speaker at a recent ANA-Australasia meeting. His talk has been edited and printed with permission.

One of my favourite subjects is Thinking. I have done a fair bit of it in my lifetime, and I will be doing a lot more in the rest of my life. It has such a strong influence on what we do that I think it is a subject of its own.

Now is the age to talk about positive thinking. People understand that in order to get benefit from life one has to move forward, to look at life and what one can achieve.

One can achieve through positivity, not negativity. It is an expression with ramifications and strength that I don't think people really fully understand. People say I must speak in positive terms, but how far does that go? Both positive and negative thinking have exceptional strength.

One Friday afternoon in an American rail yard, a worker was cleaning out a freezer van. Unfortunately while he was cleaning it he locked himself in. He knew nobody could get to him until Monday morning so he decided to document what it was like to die from freezing. On Monday morning his mates opened the freezer van and found him dead on the floor. On the walls was his documented story.

The fascinating thing was: the freezer van was not turned on. Over the weekend the temperature in the van was no lower than 13°C. None the less he died. How does a person die when the temperature is no lower than 13°C?

In a film one could say, Well, let me comment on the acting, the script

writing, the production. It is an interesting fictional situation. This was not fiction, it was real. In a real sense he wrote the script, was the actor, produced the end result. He put into effect the potential within himself with a negative end result.

Was he thinking during the time he was in that van? Yes, he was. What was he thinking about? He was thinking about, and recording, his impending death. His thought led him into a situation where his body actually gave up the desire, or the will, to live. Somehow he switched

One can achieve through positivity, not negativity.

the switch off, and he died.

A friend working at a local hospital has told stories of people admitted who are paraplegic from car accidents. Where the break occurs in the spinal cord determines what limb is affected - it can go from losing the use of the legs, to losing the use of all limbs including the arms. When these people come in they have an injury to the spinal cord but they are healthy, yet some of these people have died within three weeks. On their record is 'lost the will to live.' Imagine the thoughts of someone lying there realizing they have become a paraplegic, making the decision that this is not the way they want to live their lives, and literally their bodies just let go. They are willing themselves to death.

What messages you feed yourself is important. You need to be objective about the way you see the world. Words are so important that unless we start to utilize them and start

feeding ourselves positive information we will continue to live our lives the way they are. If you are happy with the way life is, then don't mess with it, but if you are looking to improve your life and your health then it is important to utilize words.

One problem is that people use positive thinking for a short time and expect a miracle to occur. When nothing happens they go back to their old ways. Words do have an effect. The person you are today has been put together over a number of years. It's not as easy as expecting one or two positive words to suddenly change your life. What we all need to do is make a habit of sending ourselves positive messages every day, every night, continually. In order to do that we need to be able to catch ourselves thinking.

In 'From Emotions to Lesions' published by the Roche Chemical Co. and sent to doctors in the late 1960s, there is a picture that I find exciting. It is a picture of a hand, and on that hand is a burn mark. The fascinating thing about this burn mark is that the hand was never burned. The owner of the hand simply believed the hand

continued on page 2



**Acoustic Neuroma
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of Canada**

Your comments, ideas, suggestions and financial support are needed and welcome.

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Positive Thinking

continued from page 1

was burned and, as a result of that belief, the cells actually changed in his hand to manifest a burn. This is not a figment of my imagination but has been medically documented. The connection is between our thoughts and our body.

Positive thinking: negative thinking. Do you ever stop to listen to your thinking? It can cause ulcers, heart attacks, and has been linked to cancer. Stress is nothing other than thinking-negative thinking. Thinking has a tremendous way of manifesting within our bodies. The problem is what is the predominant thought we have in the world? Is it positive or negative. To judge how people think look at the television, newspapers, radio and so forth. Most of the information given would be negative.

Why is all this negativity congregated in the news aspect? Because people are interested in the negativity and the catastrophes that happen in the world. We focus on it and the media utilize that focus by presenting the material we like to have. The problem is we become a little like drug addicts: we become used to it, and they have to do more to get information and to shock us.

However, they recognize that ultimately a feel-good message is needed, so at the end of the news bracket there is some positive aspect to ease us back from the catastrophes.

Acoustic neuroma people have suffered from a medical problem that has been the focus for a fair bit of their life. That can get a person down, I am sure. It is easy to focus on that, but there are other aspects of You.

Think of what it takes to lift up your hand and open and close it. Think of the tendons, the nerves, the muscles that work beautifully every time you open it up. That applies to other parts of our body as well. There are so many valuable, strong and positive aspects of ourselves. Instead, what we tend to do in life is focus on the minority of our concerns.

The question again is, What thoughts do we have about life? Mostly they are destructive. In so many ways we tend to have inner talk. A little voice exists somewhere

in our heads saying, "I am really never going to get that parking space," or "I will never be able to find the house I want," or "I will never get the job I want," or "I don't think that person will ever like me," and so on. Have you heard that voice? Is it all negative or is it all positive? It is all negative.

Have you ever heard it say to you, "I am a good person, I deserve the best in life, I am worthy, I am strong"? For most people most of the time the answer will be no. If it is positive, that is tremendous. Most people don't think they are worthy in life. Imagine someone sitting next to you and for 20 or 30 years, whispering into your ear, "You are not a worthy person. You are not important. You don't deserve the best." Can you imagine that after a while you become somewhat brainwashed? After a while you start to accept that information. The negative talk we have starts to have an impact on us, and our cells actually respond. We have learned to say these things to ourselves. We have learned!

I want to reverse that process and start to give myself, and suggest to other people to give themselves, different messages.

When a child is born, what does it know? It virtually knows nothing but to suckle. The child is taught after it is born, but not necessarily taught positive things. Children whose parents are concerned about them are fed information about the world. Most people just let the talk of the world go on and ignore it. Most people cannot go into a room without turning the radio or TV on, just for background noise. Without the noise, guess what they would have - they would have themselves.

Focussing on something will take your attention, such as the ringing in the ear. It will get louder. By concentrating on something else - something positive in your life with regard to health, etc. - and really focussing your mind on to it, after a while the ringing would go.

One of the most beautiful parts of our mind is that it is impossible to think of two things at the same time. For example, try to count from 1 to 10 and from A to H at the same time. You can't! The mind actually goes 1, A, 2, B extremely quickly and the illusion of the fact is that it is continuous, it is not.

I am saying, Focus on what you want out of life. Focus on what you want to achieve in your life. If you want health, then start to focus on health and well being by using words that indicate that to you.

One of the brilliant men of this century was a chemist named M.L. Coue. He found the power of the spoken word was so strong that he set up a clinic to teach his patients to use words and thoughts to help in their own healing process. One of the strongest phrases he used was, "Every day, in every way, it is getting better and better."

Because the subconscious mind listens when you start to tell yourself over and over again, "It is getting better," your cells actually listen. They will change and focus on what you seek to achieve just as strongly as those cells changed to manifest the burn mark.

Is this something new? No, it has been around for thousands upon thousands of years, but it has not been the mainstream of thinking. Mainstream thinking has been intervention, ie. drugs, operations, etc. to intervene with the body process. It does have advantages, however the aspect of self and how intervention works on self is just so important.

To conclude: Whether you think you can or can't...you're probably right.

If you think you are beaten,
you are;
If you think you dare not,
you don't;
If you'd like to win but think
you can't,
It's almost certain that you won't.

If you think you'll lose, you've lost;
For out in the world you'll find
success begins with a fellow's
will.

It's all a state of mind.

If you think you're outclassed,
you are.
You've got to think high to rise;
You've got to be sure of yourself
before you can ever win a prize.
Life's battles don't always go to
the stronger or the faster man;
But sooner or later the man who
wins is the man who thinks he ca

President's Corner



by Shirley Entis

The Vancouver Symposium and the North American Facial Study Group workshop brought to the forefront again the importance of communication, and of understanding each other's needs. To talk directly to each other, and to raise issues with others from across the country - and from other countries - creates enthusiasm and interest in the work of ANAC.

More opportunities like this are needed in order to give present

members a chance to offer their ideas, support and services; and to encourage new people to become involved. However, at the moment funds and membership participation do not allow this to happen.

We need your ideas and actions to continue. No idea is too small...or too large!

Development of the EAPAN Program across the country is beginning to present opportunity for involvement in local areas. As you will read in this issue's EAPAN report, the Montreal pilot project is preparing a document from their results to be made available to other communities and ANAC Chapters. For instance, Vancouver, after a well-deserved rest this summer, has agreed to continue the EAPAN format in their area.

Reaching the goals of EAPAN will allow members to make informed choices regarding the acoustic neuroma experience...an important issue to all.

Once again, I not only congratulate the Vancouver group for their hard work for a successful symposium, but also for their

innovative ideas for fundraising. Their persistence paid off. They held two successful casino nights to cover the costs of the symposium as well as start development of future project considerations.

We all learn and benefit from each initiative, whether it be a casino, race pledges, personal letters to friends and family, selling Association promotional items, corporate pleas, raffles, etc. Our 1-800 line is always open for you to share your ideas or acquire information from the national office. The Connection is always eager to publish your accomplishments...no funding idea/event is too small.

Remember, it is we, the members, with the development of new and innovative means of raising the funding, who allow our organization to exist and to continue to flourish.

Once again thanks to the Vancouver group for a wonderful ANAC experience.

Keep ANAC in mind while you enjoy a great summer.

Every accomplishment starts with the decision to try.

Anonymous

Those who bring sunshine to the lives of others cannot keep it from themselves.

Sir James Barrie

The glow of one warm thought is to me worth more than money.

Thomas Jefferson

No one is rich enough to do without a neighbor.

Danish Proverb

Executive Director Position Presently Vacant

We regret to announce that Lesly Round is no longer with ANAC. We wish her all the best in her future endeavors. The position of Executive

Director will be filled in the near future. It is important for ANAC's continued growth and in the area of fundraising.

Cartoon: Bonnie and Boo Boo



"Reprinted courtesy The Toronto Star Syndicate. Copyright: King Features Syndicate."

Marie-Catherine's Story

I am Marie-Catherine Lescouffair, a 44-year-old wife and mother of two (9 and 14). For the past three years, I have been working for the federal government on a contractual basis. As for my current health status, I have no hearing in my left ear and part of my tongue and chin are paralyzed. I have recovered some mobility in my facial muscles, but it's not 100%. I have some balance problems. Here is my story.

In April 1991, I started feeling some numbness on the left side of my face, one of the characteristic symptoms of acoustic neuroma (AN). In my case, the loss of balance and hearing, typical symptoms of this illness, manifested themselves gradually, and I adapted myself to them without realizing it.

My family physician referred me to a neurologist who made an appointment for a test at the hospital. The test was a CT scan which showed the tumor. That startled me, but the doctor wanted to operate on Monday, and wanted me to stay in the hospital over the weekend to hold the bed. That was a total shock! I opted to go home and have a second opinion on Monday. The opinion was the same, and surgery was booked for 10 days later.

The doctor told me I could experience facial paralysis after the operation. I had no idea what he was talking about. When I heard this news, I had two reactions. In the doctor's presence, logic took over and I asked the questions to which I wanted to know the answers. At home I was overcome with emotion. I broke into tears while preparing my son's meal. I told him I had to undergo some tests at the hospital. The news shocked him. I didn't know what lay ahead of me. I felt desperate and helpless. My husband and my circle of friends supported me as much as they could during those ten days. My family in Europe was informed at the last minute by my husband because I could not find the courage to call them. They all prayed for me, which was their way of helping me.

The days before surgery were very difficult for me. On one hand, I knew I was undergoing major surgery and I did not know what my physical condition would be when I got out of the hospital. On the other hand, we had just bought a house and our two children were 5 and 10 at the time. I started telling my family and friends, and getting organized in case I was no longer able to go about my daily routine.



**From left to right: François - my son,
Jean-Michel - my husband,
Florence - my daughter, Marie-Catherine**

In May, two months after my 40th birthday, I had my surgery. It lasted 11 hours. When I awoke the left side of my face was paralyzed.

My strength returned quickly and, apart from meals being an adventure, what worried me the most was how I was going to handle the changes in my facial features. Would I have to take tranquilizers to survive these conditions? The neurosurgeon had told me as I was leaving the hospital that my facial nerve was in good shape and the paralysis would be temporary.

He also told me there was an association for people who had AN. I hesitated contacting them because, for me, it meant that if there was a support group this operation would have long after-effects. I found this discouraging; I just wanted to forget this period and go on to something else. In July I thought it would be a good idea to get in touch with ANAC.

Back home, I was doing well physically, but for five weeks I felt like doing nothing and my eye was terribly itchy. Then I decided I had to take hold of myself. It was summertime and each day I took a walk in the neighbourhood. The children were on vacation, and I had the full support of my family, friends and neighbours (they used to say the facial problem was hardly noticeable, but I didn't believe them!). During this period, I tried to take a positive attitude, and gave myself little messages like: You are going to get well... I waited for three months before the muscles on my left side started to move again. On that day, Friday at 1:30pm, I was in seventh heaven.

I underwent physiotherapy for one year. I was very enthusiastic about this therapy. My circle of friends gave me lots of encouragement about my face, but I

thought people only wanted to say what I wanted to hear. I kept looking at my face in the mirror while I was eating, talking on the phone, and I saw I was making facial expressions that did not please me at all. Now I realize that, thanks to the facial physiotherapy, I had made progress and also that I had finally accepted what I had become with my somewhat crooked smile.

In 1992, I rejoined the workforce - I had obtained my college diploma in 1990, and I didn't want to lose the knowledge I had acquired. In my work environment, I never heard comments about my facial expression.

It would be hard to describe all the ups and downs one experiences in this type of situation; however, four and a half years later, it is easier to summarize it. The first year was very difficult. I did not buy a single piece of clothing and just couldn't look at my photo albums. Physically, I seemed all right but my self-confidence was at an all time low. I could do everything without any restrictions - drive a car, go out, work, take care of my children and do housework, etc. - but I did not feel like doing anything. Today, I can say this period was a real challenge for me. Yes, my physical appearance has changed BUT:

- * My good health is my most important asset.
- * I regained and even increased my self-confidence, and I asserted myself.
- * My spiritual life is very rewarding.
- * I have a lot more energy and I know my priorities...when I am tired, I stop and rest.
- * In the morning, I am happy to start the day.
- * The experience brought me closer to my children.

I was able to survive this difficult period with the help of ANAC. I'd like to take this opportunity to thank Dr. Pokrupa, his assistants and secretary who referred me to ANAC where I obtained moral support with the newsletters and meetings with other members in Quebec.

Since December 1994, I am ANAC's French-speaking resource person for Quebec. If you have any comments to make, please do not hesitate to write or call me.

Marie-Catherine Lescouffair
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News and Views from the Chapters

July 1996

*Contributors to Chapter News are the Area
Contacts who bring a local perspective to the Connection.
Your comments and suggestions are important to us - keep them coming.*

British Columbia

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- Heather Horgan, Vancouver Chapter Contact
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604-464-2625
- Wenda Deane, Vancouver Chapter President
T26-888 Beach Ave
Vancouver BC V6Z 2P6
604-736-1215
- Harry Kraeker, Victoria Chapter Contact
#209-1138 Yates St.
Victoria BC V8V 3M8
604-384-7530

Report by Heather:

We are pleased to have a special insert in this issue to adequately report the recent Symposium activities. Thanks to all who attended to make it such a success.

Report by Evalyn:

Congratulations and many thanks to Sheila Fauchon, daughter of ANAC member, Joyce Fauchon of Campbell River. Sheila collected nearly \$100 in pledges for ANAC in support of her participation in the Tahsis Lions Club 1996 Great Walk, June 1st. This walk was 63.5k of gravel road from Gold River to Tahsis! We are very proud of her.

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## **Alberta**

### **Report by Verna:**

- Verna Thoman, Edmonton Chapter Contact  
15216 - 63 Street  
Edmonton AB T5A 4V7  
403-456-5468

**Apr. 30 meeting:** Twenty people attended to hear guest speaker, Margaret Hess from AboutFace. She explained the purpose of AboutFace, an international organization committed to providing information, emotional support and guidance to individuals and their families and to increase public awareness regarding facial differences. She and her husband have personal experience with their son, and have found AboutFace to be of tremendous help to all three of them.

Member, Annette Uram, had surgery for AN six years ago. Last fall regrowth was discovered in such a fashion that it was inoperable. On the advice of her doctors she went for GammaKnife treatment in Pittsburgh. She explained the procedure and cost to us. The patient's view was interesting, perhaps more 'down-to-earth' than a medical point-of-view. She is very happy now and feels well. Her talk was both enjoyable, interesting and informative.

Bubble and Flat samples of the Guibor Bandage were shown, and the purpose of it discussed.

We are in touch with a stamp collector who will pay us for stamps we collect. Please tear off the stamped corners of envelopes (leaving white space) and save them for the Chapter. Bring them to future functions, to the ANAC office, or mail to me at home. This can be a profitable fundraiser if we all take part.

We also watched a video by Dr. Craig Beaver regarding memory loss and thinking skill changes after AN surgery. Although the audio was poor,



the content was excellent and enabled us to understand what changes might have occurred in our brain due it being disturbed by surgery.

Congratulations to the participants of the Great Human Race, April 18th (8k run; 3k walk). Your pledges and efforts raised over \$1100 for ANAC. See the enthusiastic team in the picture below, and this was *after* the event! A fun time that we intend to repeat next year...keep April 28th free on your calendar.



Many thanks to the Vancouver Chapter for hosting a great Symposium. As a 'first timer' I enjoyed all aspects of it: good speakers, topics, food, company...and opportunity to participate in all. Your hard work created a successful event!

June 15: A Sandy Beach, Croquet, Lawn Darts, Relaxing on the Deck enjoying the sunshine and view of the Lake - Sound like fun? It was!...this describes the 2nd annual Edmonton Chapter picnic at Alberta Beach on Saturday, June 15th. Everyone was friendly, the weather co-operated and we all had a great time. We not only shared some difficulties relating to one-sided hearing loss but thoroughly enjoyed each other's friendship and personal stories.

A meeting date for the Fall will be circulated later in the Summer. Stay posted.

## Manitoba

■ Leslie Sutherland  
36 Valleyview Drive  
Winnipeg MB R2Y 0R6  
204-837-5280

### Report by Leslie

I was fortunate to attend the Vancouver Symposium, and enjoyed meeting people from many places. Thanks to the Vancouver Chapter for their hospitality.

Although our regular meetings have stopped for the summertime, they will resume on September 3, 1996. We will have the schedule for the rest of the year at that time. Feel free to give me a call if you have questions before then. I hope summer is enjoyed by all. See you in the Fall.

## Quebec

■ Marie Legault, National Director  
9 Horne  
St. Lambert, PQ J4P 2G7  
(Sorry, no phone number this time-just moving)

■ Marie Catherine Lescoufflair, Francophone Contact  
293 Place Samson  
Chomedey Laval, PQ H7W 3T8  
514-682-8680

■ Romas Staskevicius, Montreal Chapter Contact  
6121 LaSalle Boulevard  
Verdun, PQ H4H 1P7  
514-766-6072

### Report by Marie Catherine:

**Please note: Montreal Chapter meetings are always bilingual and for more information about French translation, please call Marie Catherine Lescoufflair (514)682-8680.**

Behind-the-scenes work will be done during the summer months to make preparations for a chapter meeting in the Fall. We wish you all a great summer.

## **Ontario**

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- Frank Fusca, National NF2 Contact  
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416-495-8979 TDD

### ***Toronto Report by Barry:***

#### **Upcoming Chapter Meeting**

**Date:** July 25, 1996

**Time:** 7:00 - 8:30pm

**Place:** North York City Hall, Committee Room #3

**Guest speaker:** Dr. Bernard Hoddinott,  
Psychologist & ANAC Med. Adv. Bd member  
Question & answer period to follow.

Come & meet others who have shared experiences similar to yours.

To assure you are on the mailing list, please call me at (416) 443-8909 and confirm your address as soon as possible.

### ***Kitchener-Waterloo Report by Trenny:***

Let's Grow Together: Please call and introduce yourself, and let me know of anyone else who would like to receive notices of future meetings.

### ***London Report by Doug:***

The 31st meeting of the Canadian Congress of Neurological Sciences was held on June 25 - 29, 1996 in the new London Convention Centre.

It was attended by over 600 surgeons from across Canada and Europe.

The London Chapter manned the ANAC exhibit at the event. Although the setup of the display was delayed somewhat due to shipping difficulties it was a successful awareness project.

We have a lot of ground work to do for our cause as it is noted that other Associations are on a first name basis with a lot of doctors and have had several years exposure that we have not had.

We met and gave out ANAC literature to many doctors and explained our purpose to them. They were presented with our recruitment voucher and asked to give it to their patients. It was gratifying to meet a number of these folks who are members of ANAC. It was also an eye-opener to see the number of women doctors at this meeting and to meet them from Finland, Germany, and England. But the astounding thing of all - how young they are...that is both sexes. We wish them every success in their search to find a reason and perhaps a cure for the AN problem.

I understand there has been some progress in finding the gene of the NF1 and NF2. Eleanor and her family (her brother being the 10th one) have sent blood samples to Toronto for this research.

It may be noted the Donahue Show had a program on the 5/9/96 called 'Shocking Ways to Fix Deafness To Brain Tumors'. You can order this tape by calling 1-800-695-9370. It is very interesting.

A London meeting, in the form of a social, is being planned for September at our home. More later.

The University Hospital in London has developed a thick eyedrop, called Carboxymethyl Cellulose (2%). It must be refrigerated as it has no preservative. It was developed for people who have a sensitivity to the preservatives in other products. The Hospital Pharmacy will have more information about this product.

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!!! For Sale !!!

**Check the insert page for new
ANAC items for sale**

Nova Scotia

■ Anna Parkinson
27 Feldspar Cres.
Kidston Estate, Halifax B3R 2M2
902-477-2396 TDD

Nova Scotia Chapter Contact for Acoustic Neuroma & Late Deafened Adults Support Group

Report by Ed Morrissey:

February guest speaker was Gordon Whitehead, accompanied by his wife Dawn. Gordon gave an interesting talk on the subject of being deaf and how to best cope with the trouble.

Sixteen people attended our April meeting. Welcome to newest member, Diane Loane and husband, Darren.

Peggy and David are still working on a form for those members using 'closed caption'. This form will assist those who want to write to the TV stations and point out concerns.

We are going to man a display table for ANAC from Oct 27-29/96 at the Canadian Assoc. For Community Care Conference. Expenses will be covered by the national office. Lisa Parkinson has volunteered to chair this project. We are pleased to assist in public awareness for ANAC.

A decision was made at the May 7th Executive meeting to purchase an overhead projector. It will be portable and bright enough lighting to use with the panel-4000 lumens. The total cost will be \$949.

The May meeting was well attended with about 19 present. Guests from Halifax Metro Assoc. For the Hearing Impaired presented us with a gift of \$700 to help purchase the overhead projector. The donation is in memory of past members Morris Deacon and Alfred Boutilier. Our sincere thanks were conveyed at the meeting.

The relay system for the phone is not up to scratch. If you are having problems, please write MT&T and point out your difficulties.

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## National Office, Edmonton

### Report by Linda Gray, Program Manager:

**ANAC needs the help of experienced and enthusiastic fundraising volunteers from across Canada. Work over the summer will include developing and expanding fundraising efforts, ie. materials. Nat'l office is fully equipped to work through e-mail, fax, etc. Please give Linda or Michelle a call at 1-800-561-2622.**

Copies of a recent article on Meniere's Disease from ANA-Australasia newsletter will be sent to all requests received in the national office.

There is also a two-hour video tape of the talk available through ANA-Australasia.

### Wanted: Penpals

Ms. Meryl G. Bowers  
'The Hermitage'  
Great Western Victoria 3377  
phone: (053)562361

45yr, career interests of Bed & Breakfast accommodation; hobbies of Period home renovating, interior decorating, collecting antiques, garden landscaping. Meryl says she is divorced, no children, but three cats. Interested in Penpal from anywhere.

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Mrs. Katherine Mary King  
29 Shawlands Ave  
Blackburn, Victoria  
Australia 3130 Phone (03)9878 0576  
AN surgeries Feb/84; Jly/95; 30yr; nurse; interests of dining out, walking, music, reading, movies, her pets, cooking; comes from family of 9; lives with husband, 2 cats & dog; currently renovating their house which they love. Would like penpal from Canada, America & N. Zealand.

The office will be closed for the week of July 14-21st. However, please do not hesitate to leave us a message and we will respond as soon as possible when we return.

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"Next Steps" Reviewed

by Peggy Bray

After the AGM, discussions about EAPAN, successful tips for Chapter development, the need for accessible stereotactic radiosurgery in Canada and what our role should be, we closed the Symposium by considering our Next Steps. Together, we discussed what was of value to us during this time and what action we would take. The following comments seemed to sum up the general discussion:

Things that you have valued and learned:

- seeing real faces, matching names to faces, making connections
- learning from the professionals
- teaching those same professionals about some of the realities of AN

- updating information
- meeting people from all over
- having the goals of the national ANA explained
- meeting the Executive Board members and learning what is going on at that level

What is next for you?

- rejuvenation of chapters by sending questionnaires to Chapter members to find out what they would like
- disseminate information
- remind people who no longer feel the need for Chapter involvement that others benefit from their knowledge and experience, so encourage them to attend from time to time
- provide ongoing support
- people may be wanting ways to express themselves other than

participating in the Chapter functions, ie. fundraising, acting as a voice in a public awareness campaign, distributing the information packages developed through the EAPAN Program

- to be clear about objectives when asking for Chapter volunteers, make it easy for people to say Yes! It does not have to require a huge commitment
- work toward obtaining a GammaKnife unit in Canada
- work toward early diagnosis
- when asked questions about AN, keep it simple, then people will relate to the information and remember it, such as, "It's a benign tumor on your hearing nerve. It's operable. However, it does usually affect hearing on one side, balance and facial muscles."

Report on EAPAN

by Janey Veneziano

EAPAN was designed to strengthen and promote the organization's purposes, objectives and progressive attitudes. Its purpose statement is to improve public awareness, to further the Acoustic Neuroma Association of Canada by training volunteers to become ANAC representatives and spokespeople for fundraising and disseminating information literature to the media, to the public, and health-oriented conferences and meetings, and also in private settings.

In the area of awareness, the Montreal Pilot Steering Committee defined the target population for the Pilot Project's focus to be the Family Physician because the acoustic neuroma patient usually has initial contact with them.

The weekend preceding the Symposium, ANAC exhibited at the Canadian Conference of Family Physicians in Vancouver. Linda Gray and Judy Muirhead ably manned the display, speaking to over 100 of the doctors attending the conference and handing out information about acoustic neuroma and ANAC. It was well received and comments that were received indicated the doctors were familiar with the tumor but they were not aware of ANAC or its patient support and information.

To enhance the present information, small notepads and bookmarks have been developed by the Steering Committee as promotional materials. We believe the little pad with ANAC's name, address, phone and e-mail numbers on it will be a good reminder of our existence. These can be given out at meetings, casual conversations, mailouts, etc. The bookmark is not just for

the doctors but also for the public. It was developed at a certain size to be used for publicity in medical journals, newsletters, newspapers, etc. The information printed on it tells about the AN and its common symptoms. In the future we want to give the bookmark out in shopping centres and stores.

Publicity via milk carton advertising is also being pursued. This has already been done for several years in western Canada on the Lucerne cartons, and we thank them for their support of charitable works. It is free publicity and once a French request and artwork submission is made to the Quebec companies we will enter a waiting list and hope to see it printed next year. We encourage members in other provinces to look into this and obtain materials for such a project in their area.

The association for family physicians has also been contacted. It publishes a magazine for family physicians, and has indicated their need at times for fillers. Our bookmark is an ideal size for them to keep on file for just such occasions. When used as a filler it is on a no-charge basis. Other medical magazines will be approached regarding similar needs.

Packages to be sent to libraries are being prepared for mailing. These were suggested as members indicated these were the first place they looked for information and found nothing.

Although not finalized yet, a booklet entitled, Acoustic Neuroma Surgery Hospital Discharge Information has been developed. Compiled to fill a need, it has information pages on six areas of post-surgical concerns the patient may encounter, as well as pages to record information on prescribed medications,

appointment dates, and questions to be answered. Its goal is to give the patient pertinent information to take home and have available if questions arise during the recovery period. It is purposely generic to tailor it to a variety of hospitals across Canada. Distribution will begin in the Montreal area.

The latest accomplishment has been an Information Day held May 25th - Montreal. Its agenda provided four workshops with facilitators speaking on Medical Perspective, Coping Strategies, Money Matters (fundraising), and A Voice for Acoustic Neuroma. It also provided the 30-35 participants with the opportunity to get together and become better acquainted.

Many thanks are extended to the facilitators, especially Frances Ravenbergen, Julie Sklivas, and Community Education Services CECM, for their time, expertise and presentation which made the day enjoyable to all. Evaluation forms indicated many were interested in Coping Strategies and having a follow-up workshop on this. Approximately 20 wanted to become Voices for Acoustic Neuroma, and Fundraising offers came from four others.

The day was deemed a success by all, and we are presently evaluating the workshop and preparing a program manual to enable other interested chapters and individuals across the country to continue the journey of reaching out.

We've been fortunate to have people come and help from all spheres: work, family members, and people who have recovered from acoustic neuroma treatment. Having support, enthusiasm and cooperation from people like those attending the workshop will help the Project proceed quickly.

FROM *the* PATIENT'S POINT *of* VIEW

Symposium Report

by Heather Horgan, Planning Committee member
photos by Laszlo Czanyi

The 1996 ANAC Symposium, *From The Patient's Point of View*, was held at the Century Plaza Hotel in Vancouver on May 31, June 1 & 2. Verbal and evaluation reports both indicate it was a very successful and positive experience.

The weekend was preceded by a two-day conference of the North American Facial Therapy Study Group hosted by ANAC and organized by therapists Jackie Diels, Brenda Ross, and Susan Rankin. This was attended by 24 facial therapists from Canada and the United States who met to learn and discuss the most up-to-date assessment methods and treatment techniques. Keynote speaker was Dr. Robert Anderson of Fort Worth, Texas who addressed Surgical Anatomy, Physiology & Reanimation of Facial Musculature.

Several of the therapists stayed to attend the ANAC Symposium and be included in the 75 registrants. This included many of the provinces, United States and England.

The weekend started with a social evening on Friday night. As we all know, background noise and chatter are usually annoying to us, but somehow it was very tolerable that night as we made new friendships and re-acquainted with old friends.



New Medical Advisory Board Chairman,
Dr. Robert Broad

The Saturday agenda began with the investiture of well-known neurosurgeon, Dr. Robert Broad of Edmonton, Alberta as new Chairman of the Medical Advisory Board of ANAC. He will be continuing on from Dr. Charles Tator, founding Chairman.

It was wonderful that so many members could welcome him to his new position.

Saturday was a full day of information, including views on the future of treatment options for acoustic neuromas including

GammaKnife, LINAC, and microsurgery. Dr. Fraser Noel and Dr. Michael McDermott shared their knowledge on these topics and answered questions from the group.



Dr. Fraser Noel

Before their presentation, they kindly and expediently rushed across the street to St. Paul's Hospital to borrow and set up some audio-visual equipment as there was a malfunction in the available equipment. What versatility!

Other topics covered were balance retraining, communication after hearing loss, post-surgical impact on mental function, facial neuromuscular retraining, Botox treatment, current surgical management of VII nerve palsy, mind-body healing, and the importance of humour.

Many registrants took advantage of the exhibits and displays for neck/back massage, makeup demonstrations, and obtained information from the Vestibular Disorders Association from Oregon. On Saturday evening everyone enjoyed a wonderful banquet and more socializing.

Sunday morning saw still more enthusiasm for the Annual General Meeting. We were pleased to have Mr. Karl Benne, Management



Key Note Speaker,
Dr. Michael McDermott



Sue and Bob Clifford of ANA - Britain

Consultant for Health Canada, attend to learn more about our organization. Sue Clifford, representing the British Acoustic Neuroma Association, presented Shirley Entis with a lovely lace memento made in their city of Nottingham, England. This will be framed and hung in the ANAC National Office in Edmonton. The morning ended with an interesting group discussion where Shirley Entis, Wenda Deane, Virginia Garossino, and Peggy Bray gave us food for thought as we contemplated The Next Steps for our organization.

Thanks go out to Mr. Roy Lisogar and his attentive staff of the Century Plaza Hotel, all the speakers, the Vancouver Planning Committee, Edmonton office, and all the volunteers who helped with casino night and at the Symposium.

We look forward to hearing from our Chapters across the country for their interest in hosting our next Symposium!



Symposium Planning Committee (L-R):
Wenda Deane, Tom Riglar, Heather Horgan, Peggy Bray

1996 MEMBERSHIP NOW DUE

Association pour
les Neurinomes
acoustiques du Canada



Acoustic Neuroma
Association
of Canada

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MEMBERSHIP

Please enroll me as a 1996 member of the
Acoustic Neuroma Association of Canada

Enclosed ☐ \$28 **new/renewal membership**
☐ \$200 life membership
☐ (\$0) economic hardship

Name: _____

Address: _____

City: _____ Province: _____ Postal Code: _____

Phone: (Bus) _____ (Res) _____ Age: _____ (optional)

I am

☐ Acoustic Neuroma patient

☐ Family Member

☐ Medical (Specialty)

☐ Other

I Agree

to share name/address with other patients

to receive names of others

to give local help when needed

to support research

to be informed of new treatment developments

to participate in local functions

(Please ✓) YES NO

☐ ☐

☐ ☐

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Comments: _____

DONATION

Please accept my donation of \$ _____ to the Acoustic Neuroma Association of Canada.

My type of donation is indicated below.

___ General ___ Memorial ___ Anniversary ___ Birthday ___ Other _____

___ In Memory ___ In honor of _____

Send card to _____

Address _____

_____ Postal Code _____

...Remember your friends, relatives and family on their special occasions of birthdays, anniversaries, holidays and/or memorialize the passing of a friend or relative with a meaningful gift - a donation to the Acoustic Neuroma Association of Canada.

Thank you for supporting the TEAM (Together Everyone Achieves More)

Charitable Donation # 0677682-11



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,
If not for ANAC, I wouldn't have discovered GammaKnife treatment, which I believe was the right choice for me.

Judith Montgomery
40 Sharron Drive
Toronto ON M4G 2A6

Dear ANAC,
I enjoyed the very informative article on Dr. Noren and GammaKnife in December's issue of the Connection. I was not aware Dr. Noren had relocated to the US. I am glad the Connection was able to portray GammaKnife as a possible alternative to microsurgery. It worked for me. I was beginning to feel lonely in Canada.

I underwent the GammaKnife treatment in Sweden by Dr. Noren 5 years ago. I was not considered a suitable candidate because of the large size of my tumor, around 4.5 cm. It had grown 1cm in one year but the growth has been arrested. The only side effects I have are loss of hearing in the affected ear and tinnitus.

May Sterpan
204-810 Canterbury
Ottawa ON K1G 3A8

Dear ANAC,
Please accept this donation on behalf of my mother, Ann Sjogren. She was featured in an earlier issue of your newsletter. She had her acoustic neuroma removed in 1990 after 11 hours of surgery. She has been doing very well ever since and we are very proud of her.

My mother mentioned in her article that her husband, two sons, daughter and her friend helped her after the operation...well, I married my friend and instead of sending shower thankyou cards for our four wonderful bridal showers, I wanted to donate the money to ANAC. I hope it will add to the research that helped my mother through her illness. Thank you.

Chad & Sus-Ann Hagstrom
Forestburg, AB

Dear ANAC,
In December 1994 at 36 years old, I learned about my 3.5cm AN. It was just two weeks before departing on a 3 week trip to Europe - a trip we had planned for over two years.

Even if I knew something was wrong with my health it still came as a big shock to my husband and me. We went anyway but it just wasn't the same. My headaches worsened...

At first, when the doctor explained all the after surgery problems like: facial, shoulder and throat paralysis, etc., which in my case were more than possible

considering my AN size and location, I simply did not want to believe that. Not me, I said to myself. My response to him has been: Now that I know about this tumor, I want it out of my head as fast as possible so I can start working as fast as possible. I've always been a fighter. No obstacle is big enough for me, I thought - until I woke up after 9 hours of surgery!!!

When people asked me how I felt I simply replied, I just feel like a huge bulldozer crushed me.

I thought it was the end of my ordeal when in fact it was the beginning. Although my facial nerve was saved, four days after surgery my face started to paralyze and the paralysis became complete in three days. Vertigo started five days after and lasted for two months. I got a bit depressed as well.

Ten months have passed and I would say that my facial condition has improved about 75%. I lost my hearing completely on the right side, and I do not walk straight but overall I feel great.

This summer I got back in shape by cycling a lot with my husband. I've always been physically active and could not believe how much damage was caused by all the inactivity. Basically, the open eye problem was the biggest obstacle for me. Just walking demanded a lot of my eye because of the dryness created by it. Just being able to drive my car again was so comforting because living in the country, for me driving was a sign of liberty.

By reading all the ANAC letters, I now consider myself lucky. Exactly three months after surgery I got back to work. It's true that I have a very understanding boss, and I want to take this opportunity to thank him for his support and compassion throughout it all. A special thanks to my dearest husband and daughter-in-law who were there all the way, during nice and not-so-nice moments. Of course, I do not want to forget Drs. Mansour, Mohr and Dufour, Mrs. Entis and the staff at the Jewish General Hospital in Montreal. I could not have gone through it without you all.

Now I know the true meaning of: The Hope Is Recognition and Treatment.

Noline Vallée
95 Croissant L'Heureux
St-Charles-sur-le-Richelieu, PQ
J4V 2Z4

Dear ANAC,

Many thanks for all the information you provided on the phone and by mail. It would not have been possible for me to conclude that GammaKnife surgery was for me without your considerable assistance.

I can report that I went to Providence Rhode Island Hospital and on Sept 27/95, with the help of Dr. Noren and his expert team, completed the procedure without any bad side effects. So much so that I need not have stayed in the hospital/hotel overnight. Needless to say I had a good night's sleep.

I feel, now, much as I did before the operation, which is pretty good considering I can use my bad ear on the telephone and have balanced hearing.

Ontario paid all the charges that amounted to about \$42,000CDN. This was a nice birthday present for Sept 28/95.

I am optimistic that in time my hearing will improve to normal.

May I thank you once again for your invaluable help. I could not have managed without it.

Gordon Dabbs
17 Thorncrest Road
Islington ON M9A 1R8

Dear ANAC,

On October 19, 1995 at St. Paul's Hospital under the expert care of surgeons Griesdale and Noel, I had a 2cm AN removed from the right side.

They completely saved my facial nerve, the only thing I feel is a spot of numbness of my tongue. The noise in my head gradually diminished and was completely gone after 6 weeks of surgery. My balance is nearly back to normal, I was able to go skiing 3 months after surgery, I was wobbly the first day, but on day two I was my same old self. Getting used to only one functioning ear is easier than I thought, I am grateful that God made us with spare parts.

About 2 months after surgery I started experiencing cranial headaches more or less on a continuous basis. It is then that I decided to contact ANAC. When I explained my problem, wanting to know if that was normal and something to be expected, I was promptly sent all the free information you had on the subject of headaches...and all I ever wanted to know, or not know, about AN. After reading the literature, I feel very fortunate for the way I am. Thank You for being there.

Doreen Sicotte
501 Zdrakle Cove
Kelowna BC V1Z 3J7

Hints from Head Office

By Linda Gray,
Program Manager ANAC

Listen, educate, support and give reassurance.

As an employee in the ANAC national office I look forward to the inquiries on our 1-800 number. They involve many different aspects of acoustic neuroma, and often the conversation is more relaxed once the caller is made aware I have both personal and office experience with AN.

Everyone learns something about acoustic neuroma, anything from: asking about the unusual, tongue-challenging name, to medical professionals who want to help their patients, to personally being in the acoustic neuroma experience - perhaps searching for a diagnosis of symptoms, experiencing the emotions attached to a recent diagnosis of such a serious condition, or struggling with some of the surprises that come during the recovery after treatment.

The questions are always valid and important, and usually give an opportunity to search or revise information. I often feel I personally have acquired more knowledge through talking, explaining and learning.

The following are some general suggestions offered during many of the calls. These suggestions are basic but important. By printing them I hope others will find them helpful. The comments can be used in most situations, not only medical. Pass them onto family and friends too.

1. All questions are good questions. No question is too small.

Even though it appears to be something that would be known by others, ie. medical professionals, if it is a question for you then it requires an answer. Sometimes it is a surprise to find it is not common knowledge and you have helped others by asking.

If you do not feel you have been given a complete answer for your understanding, either follow it up at your next appointment, or take it to someone else for a second opinion.

2. Bring someone with you when attending an important medical appointment.

Being personally involved makes this an anxious time for you and stops you from being objective. Emotions can often cause you to forget questions you were going to ask. Bring someone who is calm, objective and can help to make sure the appointment is a positive experience.

Also, appointments are usually scheduled for a small amount of time and the patient may feel rushed. There is sometimes a feeling of taking up important time of the professional, or imposing on someone else's appointment time. However, your questions are important and having time to obtain the answers will give you and the professional an understanding of the type of information you want. Having someone along helps to reinforce this.

There is usually benefit for both you and the accompanying person. Usually it is someone closely involved with the situation - a spouse, family member or good friend. Being able to go along will help alleviate some of the unknowns and fears they are experiencing, too.

3. Make a list of your questions. At home or work, every time you think of a question jot it down.

You will find the professionals will appreciate your list because they then know how much information you are searching for...some people want to know everything, some want to know nothing, and there are those of us in between. The professionals do not know you personally and cannot know how much information to give you at any one time. This list will be of great assistance.

Also, you will not have to worry about forgetting the questions before the appointment date arrives because it's on the list!

4. Talk over your feelings with someone close to you - someone who is understanding and a good listener.

An emotional rollercoaster is normal for such a situation. Experiencing shock, anxiety and panic is normal for the information you are being given. It is okay to cry, be angry, and want to blame someone/something for what is happening. However, if you keep those feelings inside it is more difficult to approach the situation with an open mind, to go beyond those negative emotions. Clear thinking is important in order to understand and accept the information being presented to you.

5. Keep an open mind. Information can be gathered in unlikely surroundings and situations. Gather as much as you can before deciding what is right for you.

Remember, the more information acquired, the easier it is to comprehend, understand, and work with a situation.

Guibor Bandage Price Re-evaluated



We have found the original stated price of the Guibor Bandage does not cover ANAC's costs of the item. Because of this, postage and handling must be charged on all future orders.

The revised prices are:

Members \$35/pkg of 10;

Non-Members \$45/pkg of 10.

Name Sharing Is Appreciated By Many

ANAC receives several letters each week from AN people interested in networking with others in their area. Some of their questions include:

- who has had the treatment I am researching?
- who has similar problems to those I am experiencing?
- who will keep in touch with me and help me through this time?
- who can I visit in my area and form a common bond with?

ANAC feels strongly about sharing members' names only after their permission has been obtained. We do not share mailing lists with other organizations, or sell them for advertising purposes.

We want to give as many contacts as we can to new acoustic neuroma people interested in local networking. However, many of the names in our files have not indicated their permission is given.

So please, when filling in the 1996 membership application, take a few seconds to indicate Yes or No regarding sharing name/address with other patients. It will help us to help others. Thanks!

TEAM:

Together Everyone Achieves More

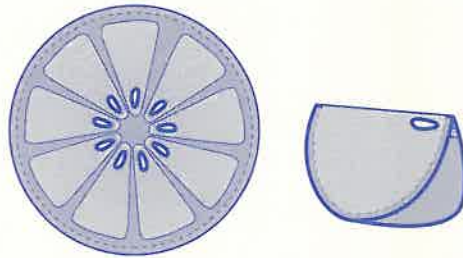
The Lemonade Stand

Life served us lemons ... so let's make lemonade

Life served us lemons...so let's make lemonade

A column of personal recipes for using the lemons of life to make something more palatable.

- I have found there is humor in memory...or lack of memory. It is frustrating to continually retrace my steps to retrieve what I forgot to get the first time, but I get exercise! And, I enjoy the reminder of not taking a shopping list to the store every time I open my cupboard and find 3 jars of mustard and 3 bottles of VIM, the cleaning agent!
- I found a hairdresser who will come to my house...very helpful indeed when I don't feel up to going out in public, or find it hard to wash my hair and keep soap and water out of my eye.
- There may be a make-up artist in your community who would come to the house and show you how to compensate for asymmetry, etc.
- When in a restaurant don't be afraid to ask for the music to be turned down, and to ask for seating arrangements to accommodate hearing suitable for your group.
- Request of the airport staff that they make sure you hear their call for your flight.
- A artificial tears product called Tear-gel works well for me, especially at



night. It is thicker than tears but not as thick as ointment. It comes in a tube, and don't hesitate to ask for it if it is not on the shelf.

- Winter Care: Beware the weak side of the face can become very cold in a short time. Take extra precautions to ensure against frostbite and make sure the eye is well protected.
- Be honest about your deficits. Try not to hide, ignore or pass them off as inconsequential. People can work with problems easier if they know what they are.
- Don't ignore your health. See a physician regularly for a medical and see a dentist and ophthalmologist routinely.
- I have found that wearing swimming goggles is inexpensive and effective for my dry eye problem.

Find it! Treat it! Beat it!



Acoustic Neuroma is a benign brain tumour affecting the functions of the inner ear. It is often misdiagnosed or undetected. If any of the following symptoms persist, consult your physician.

Common Symptoms

- One-sided deafness, gradual or sudden
- Balance problems, unsteady gait
- Facial numbness, tingling, spasms
- Headaches
- Dizziness
- Visual disturbances
- Tinnitus (ringing or buzzing in the ears)

Special Thanks to Our Contributors

March 1, 1996 to June 15, 1996

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.

Special thanks to:

Verna Thoman
Shirley Entis
Therapeutic Alliances Inc.
for their most generous
donations to ANAC

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Irma Arnold
Box 42, Site 305,
Wasaga Beach, ON
L0L 2P0 705-429-2484

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Call the person listed in your province to obtain a contact name in your area.

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Heather Horgan
3011 Reece Avenue, Coquitlam, BC,
V3C 2L1 604-464-2625

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T5A 4V7 403-456-5468

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This organization gratefully acknowledges the
financial support of Health and Welfare Canada.



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Please enroll me as a member of
Acoustic Neuroma Association of Canada
Box 369, Edmonton, AB, T5J 2J6

Name: _____
Address: _____
City: _____ Province: _____ Postal Code: _____
Phone: (Bus) _____ (Res) _____ Age: _____ (optional)

I am ☐ Acoustic Neuroma patient ☐ Family Member ☐ Medical (Specialty) ☐ Other
I Agree (Please ✓) **YES** **NO**
to share name/address with other patients ☐ ☐
to receive names of others ☐ ☐
to give locally help when needed ☐ ☐
to support research ☐ ☐
to be informed of new treatment developments ☐ ☐
to participate in local functions ☐ ☐

Comments: _____

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