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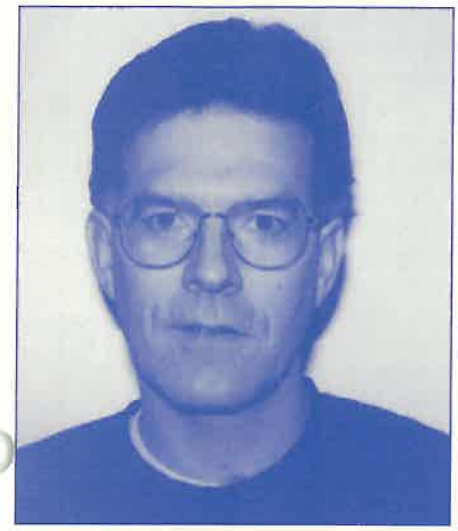
Botulinum Treatment for Facial Spasms



by Ross Kennedy, M.D., C.M., F.R.C.S.(C)

Dr. Ross Kennedy, Professor of Ophthalmology, Department of Ophthalmology University of British Columbia, recently spoke to the Vancouver ANAC Chapter about the Botox treatment for facial spasms. The following article is a transcription of his talk and his answers to questions from the group.

The drug known chemically as botulinum A exotoxin and commercially as Botox was developed by Dr. Allan Scott, a pediatric ophthalmologist who pioneered the medication and treatment. Dr. Scott has dedicated his life to this marvellous work.

During its original trials, botulinum was found to be helpful for facial spasm disorders as well as its original intent for treatment of eye alignment disorders. This has led to its use for twitches following AN surgery as well as other types of primary muscular twitches and spasms.

Basic Considerations

The acoustic (VIII cranial) nerve and the facial (VII) nerve grow out of the brainstem close together and are difficult to separate. The acoustic nerve supplies sensory innervation to the ear. The facial nerve exits the skull just behind the jaw, branches out across the side of the face and supplies muscles of the face.

This branching pattern explains why some people with facial nerve problems have symptoms confined around the eye while others have mainly involvement of the side of the face. Different parts of the nerve may be selectively involved.

During its original trials, botulinum was found to be helpful for facial spasm disorders as well as its original intent for treatment of eye alignment disorders.

Think of a nerve cell as an octopus. It has a central cell body with many branches running from it. A peripheral nerve is a collection of branches of various nerve cells plus supporting tissue. If one branch is cut it may regrow a certain amount depending on how far the cut is from the central body. The more peripheral the injury, the more likely the nerve branches will regenerate. For example, when someone cuts off their arm the nerve branch, or tentacle of the octopus, is far from the root or cell body in the spinal cord. This is called a peripheral injury, and has a much higher chance of recovery than damage to the spinal cord or brain itself.

The peripheral branches of nerve cells are encased in a supporting structure much like the insulation covering electrical wires. When a peripheral nerve is damaged, the end closest to the cell body may start to regrow.

The neurosurgeon carefully reconstructs the peripheral nerve after injury because if the supporting structure is intact, the new nerve sprout has a chance to grow back to resupply the area previously serviced by the damaged nerve. The supporting structure is important to help the nerve grow back where it is supposed to.

It is difficult during AN surgery to separate the tumor from the nerve and to spare the facial nerve. Loss of function occurs when the facial nerve is damaged and the regenerating nerve branches can't find their way back to their original area, or for some reason do not grow at all. The patient notices that the face droops because of lack of nerve supply to the facial muscles.

Abnormal facial movement results if the nerve is disrupted and the new nerve rootlets find their way to structures they were not intended to innervate. For example, the brain may order a smile to be produced. After misdirection of the regenerating

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Acoustic Neuroma Association of Canada

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

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Botulinum Treatment...

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nerve fibres occurs, the brain is unable to control the correct muscles and an abnormal facial movement occurs. The upper face may move instead of the intended smile.

Normally muscles contract to create fine motor nerve movement. However, when the nerve fibres branch back after surgery they may 'capture' more muscle bundles than they did originally. Movements will be coarser than previous and may be difficult to control. What used to be a fine, well controlled movement may become a spasm.

Synkinesis occurs when activity in another group causes fibres in the damaged facial nerve group to work as well. The reason for this 'linked' action is unknown. It can't be explained by what we know about the healing processes of peripheral nerves. Synkinesis can occur when chewing (innervated by a totally different nerve trunk) and the facial nerve fibres of the facial muscles fire also. The face contorts when the person chews.

All these effects can happen after AN surgery. The surgery is delicate and the final effect on the facial nerve depends on where the tumor is situated and how much manipulation of the nerve is needed to remove the tumor.

Treatment For Abnormal Movements: (Remember how the system works...the brain starts the impulse, it travels down the nerve root and activates the muscle.)

If there are inappropriate, overactive movements, or spasms of the muscle, several methods can be used to stop it:

1. Sedate the brain. A tranquilizer is given to stop the twitching through suppressing the origin of the nerve signal to the muscle in the brain. Since you don't want to stop other brain functions, the drugs needs to be custom-made to emphasize muscle relaxing properties without being too much of a general brain suppressant. Examples of centrally acting medications are Tegretol, etc.

2. Cut the nerves. This stops the spasm by interrupting the communication between the brain and the muscle. The side-effect is no more movement of the muscle. If there is a spastic muscle after a facial nerve paresis, the muscle fibres in the facial nerve can be stripped out. It is possible to cut the skin in the area where the facial nerve branches to the facial muscles in front of the ear. With a nerve stimulator one can find the twitching branches that service the area. Those nerve fibres can be preferentially selected out and destroyed.

Unfortunately that nerve will sprout again (50% of patients have recurrence of spasm within 2 years).

3. Local anaesthetic. The spasm will stop but only temporarily.

4. Work directly on the muscle with Botulinum.

The botulinum organism grows in the soil. One of the toxins produced by this bacteria is very, very selective for paralyzing human voluntary muscle.

The botulinum A exotoxin works in a very predictable way. If injected into a muscle there is no obvious effect for the first 24-48 hours. The chemical binds to the muscle and stops the nerve from communicating to the muscle. The muscle is still intact and will work if directly stimulated electronically, but the communication between the nerve branch and the muscle fibre is disrupted.

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President's Corner

by Shirley Entis

Several members across the country are becoming more officially involved in ANAC's activities. These changes were announced during the Board of Directors conference call held in June.

Let's start with the head office in Edmonton. Jan Stuckey, employee for nearly 8 years, has recently resigned her position and will be greatly missed in the office. Verna Thoman, and recently Michelle Rurka are employed several hours each week and are available to take your calls. Each has specific duties and will work with Linda Gray to complete the many tasks of the national office.

Some changes were made on the Board of Directors, too. Sharron Foster unfortunately had to step down as Treasurer due to personal reasons. However, we are pleased to welcome Jan Stuckey as Treasurer and representative for Alberta.

The contacts across the country have also seen some adjustments. Two women have stepped forward and volunteered for contact positions. Leslie Sutherland, Winnipeg, will be replacing Doug Cullens, who has resigned after several years of service. Barbara Theriault, New Brunswick, has offered to set up the contact system for that province. Welcome to both ladies and we look forward to hearing more from you in future issues.

Watch also for a new reporter for the NF2 News (formerly Bilateral Link) in this issue. Marjie Lesko has kindly accepted the position following Frank Fusca's retirement. He will be continuing as national NF2 contact person and will remain active behind-the-scenes in gathering and updating NF2 information.

I would like to ask all of you across the country to call your contact people and offer your suggestions, ideas and support. They want to hear from you. They want to know how you are doing, and they want to tell you how ANAC is doing. Let's continue the communication of support and education.

Hope you all have a wonderful summer.

P.S. We are all excited - EAPAN is here! ...see the article on it in this issue. Will you join us?

Botulinum Treatment...

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None of the toxin seems to be absorbed systemically - it only goes where it is injected. A patient does not normally develop antibodies to it.

After approximately one week the clinical effect is reached. (The muscle spasm stops). This effect lasts usually 12 weeks with some receiving benefit as long as 6 months to 1 year. The effect always wears off.

Side-effects have mainly to do with where the drug is injected. So, for example, if the injection was done around the lower eyelid and the positioning was not exact, the eyelid would droop. That is not really a side-effect, but more correctly, the right effect in the wrong spot.

Botulinum is a well-known drug with a long history. It has been around for thousands of years. It is chemically well-known and has been used clinically for 15 years; it has been a prescription drug for 4-5 years and an investigational drug for a period before that.

Editor: If you feel this treatment might be of benefit to you, please discuss it with your physician.

Questions from the members regarding Botulinum treatment

Q: Is there an antidote to use if in fact there is a kind of overreaction?

A: Theoretically, there is an antidote, an anti-botulinum-toxin toxin, but I have never heard of it being used.

Q: So basically you just wait for the effect to wear off?

A: Yes. Sometimes if the blink reflex is depressed, the eye will dry out and tearing problems will result. Artificial tears are then prescribed. In the context of AN, side-effects are rare because most of the problem is with the upper face.

Q: Will the muscle atrophy over time?

A: Information regarding muscle atrophy is taken from the original research where monkey muscle was injected time after time after time. It showed 'disuse atrophy' similar to the aging process. That occurs with Botulinum on a microscopic level, but not on a practical level. In fact sometimes, in people who have repeated injections, the duration of the effect drops down, the reverse of what is expected. People don't allow the spasm to become as severe as when they started the program and return sooner for another injection.

Q: When would the spasm occur after surgery? Does it occur at any point or does it occur immediately after surgery?

A: The question really is, "How long does it take for the regenerated roots to grow and serve the muscles and skin again?"

In the context of AN the spasm is not usually caused by irritation but comes after aberrant regeneration. If the growth rate of a nerve is approx. 1cm/month, then it should take several months after surgery to develop a spasm.

Q: I had a facial nerve transfer and now my eye moves as I am eating. Is the facial nerve you are describing the same one causing this problem?

A: The facial, or VII cranial nerve, supplies the superficial muscles of the face. The V, or trigeminal nerve, supplies the muscles that enable chewing. When muscles supplied by both the V and VII nerves fire at the same time it is called synkinesis. There is not a good explanation of why this occurs.

Q: Will it go away?

A: I have seen it change, and disappear, over time in children who have abnormal movements of the face when they chew.

Q: Does their age improve that possibility?

A: No, no one knows why it happens so it's difficult to explain why it goes away. Unknown causation also makes it difficult to treat.

Q: I'm 25 years post-op AN and in the last approx. 7 years occasionally when I eat, especially something hot like soup or hot tea, my eye waters slightly. This is wonderful because normally it is dry, but increasingly in the last 4 years since I had my gold weight inserted my nostril drips when I eat!

A: Great! (in that it helps the ocular dryness)

Q: I find I'm not the only one. There are other AN people experiencing the same thing.

A: Although the facial nerve is mostly a motor or muscular nerve, there are other little branches, one of which supplies specialized fibres to different parts of the body, such as the tongue, lacrimal gland, etc.

When the facial nerve is damaged after AN surgery it starts to regrow. It is not unusual for some of the fibres to grow back and serve the lacrimal gland causing the mis-wiring phenomena we talked about before.

Q: Would you only use Botulinum if the synkinesis is severe? For example, would you do the injection for me because my eyelid closes when I chew although it is not severe?

A: When to treat deals with the philosophy of medicine. My philosophy is 'if someone takes the trouble to come and see me I do what they ask me.'

Q: If you had injections for a few times and then decided it was not worth it, is there any reason why you would have to keep taking it? Can you stop and things would be the same as before you started?

A: Things would be as if you didn't touch them. You can stop at any time.

Q: Can you explain why, when you have a dry eye, sometimes it's more dry than other times? My eyelid started twitching for a few days and then it stopped. This has never done before.

A: There are many different reasons why it could happen: perhaps an air conditioning vent, a new office, water supplies, evaporation, temperature, certain drugs, ordinary antihistamines, etc.

Q: Can stress have any effect on the spasm?

A: It certainly does.

Mary's River: Wren, Oregon

by Alison Townsend

There is no message in the
river except how to move
slowly, one muddy fin of
light at a time, learning to
thrive in the curves and
marshy places; letting growth
come from gravity; your
whole life a channel carved
deeply between bright
green banks.

NF2 News

by Marjie Lesko

Thank You, Frank!

Many thanks to Frank Fusca for dedicating his thoughts, ideas, and energy to the Bilateral Link over the past five years. Frank's foresight to address issues and share stories relating to individuals with bilateral ANs has been beneficial to all. He has decided to leave the Bilateral Link now and focus his energy on personal contact with other NF2'ers. The time he has dedicated to the Bilateral Link is sincerely appreciated.

Hello, Marjie!

A big welcome to Marjie Lesko and NF2 News. Her first article for the renamed column, NF2 News, follows. Marjie's interest is as a family member; her brother was diagnosed with NF2 two years ago. Since then, at her home in Victoria, BC she has dedicated much time to reviewing medical articles on the disorder and contacting medical professionals worldwide to gain more information on NF2.

Hello everyone.

As the majority of individuals with bilateral ANs also have the genetic disorder, Neurofibromatosis 2, my goal is to relay information, both medical and personal, as it relates to NF2'ers, family, and friends. Please pass on your ideas, suggestions, or queries for future issues and I will try to incorporate your requests. Write Marjie Lesko c/o ANAC, Box 369, Edmonton AB T5J 2J6.

For your interest here is a list of other newsletters focusing on NF2. Do you know of any others?

Evergreen
The Evergreen AN Support Group, 7910-350th St East
Eatonville, WA USA 98328
(206)847-0656

iNFo
BCNF Foundation, #909 - 750 W. Broadway Vancouver BC
V5Z 1H8 1-800-385-2263

Neuro-fibro-matosis
The National Neurofibromatosis Inc. (NNI), 16th Floor 95 Pine St, New York, NY USA 10005
1-800-323-7938

neuro-fibrom-atosis
NNI - Michigan Chapter, 244 Birch Hill, Rochester, MI, USA
(810)351-4350

NF2 Review
House Ear Institute, 2100 West Third St., Los Angeles, CA USA 90057-1902

NF International
International Neurofibromatosis Association, P.O.Box 270313, Tampa, FL USA 33688
Ph/Fax (813)935-0549

Stereotactic Radiosurgery for Bilateral Acoustic Neuromas

Because of the increasing documentation on the effectiveness of stereotactic radiosurgery (SR) on acoustic neuromas (AN)[1], individuals with Neurofibromatosis 2 (NF2) are more often being considered for this treatment. (See 'Gamma Knife Radiosurgery For Treatment of Acoustic Neuroma' in Vol.7 Issue 2 for description of the treatment.)

However, people with NF2 need to be aware of many factors before choosing SR as one of the treatments for AN(s). To date, the majority of medical articles documenting SR treatment focus on both uni and bilateral ANs without a specific breakdown of results between the two. Because unilateral and bilateral ANs differ in surgical anatomy a treatment's success may be more or less dependent on that factor.

The following is a summary of one published medical journal article2[2] that specifically focuses on the effects of SR on individuals with NF2 and bilateral ANs.

Criteria to consider when deciding on treatment for ANs includes tumor control, hearing preservation, facial nerve damage, **trigeminal** nerve damage, and any other related **neuropathies**. In the article, tumor control was noted in 90% of the group treated with 40% of the tumors decreasing in size after one year follow-up (10% of the treated tumors increased in size). Hearing preservation, serviceable with the use of a hearing aid, was noted in 33% while without a hearing aid no hearing preservation was noted. Facial nerve damage was documented in 7/19 (37%) - four of which were new facial neuropathies while the remaining were further deterioration on an existing neuropathy. The occurrence of facial nerve damage was not significantly associated with tumor size but was with maximum tumor dose used during SR. Trigeminal nerve damage was noted in 26% (5 of 19) individuals with three of the five having developed new trigeminal nerve damage. Other neuropathies arising from SR included transient headaches and/or nausea which were resolved with mild analgesics and antiemetics.

At the time of writing the authors agreed further follow-up was necessary to establish the permanence of tumor control using SR treatment. It was also suggested lowered radiation doses may improve hearing preservation. However, it is unknown what effect the lowered tumor dose will have on tumor growth control.

This summary is by no means offered as a substitute for informing yourself and seeking professional medical opinions. I strongly urge reading the information noted below and consulting with a physician(s) before making treatment decisions.

[1]Contact ANAC for a listing of articles focusing on the treatment of acoustic neuromas with stereotactic radiosurgery.

[2]Linskey, M.E.; Lunsfoed, I.D.; Flickinger. J.C. Tumor Control after Stereotactic Radiosurgery in Neurofibromatosis Patients with Bilateral Acoustic Tumors. Neurosurgery, Vol. 31, No. 5, November, 1992.

Editor: *"Since 1992, the University of Pittsburgh has published a significant reduction in the complication rate due to the decreased dose and better computer dose-planning." Medical Advisory Board member, Dr. Douglas Kondziolka.*

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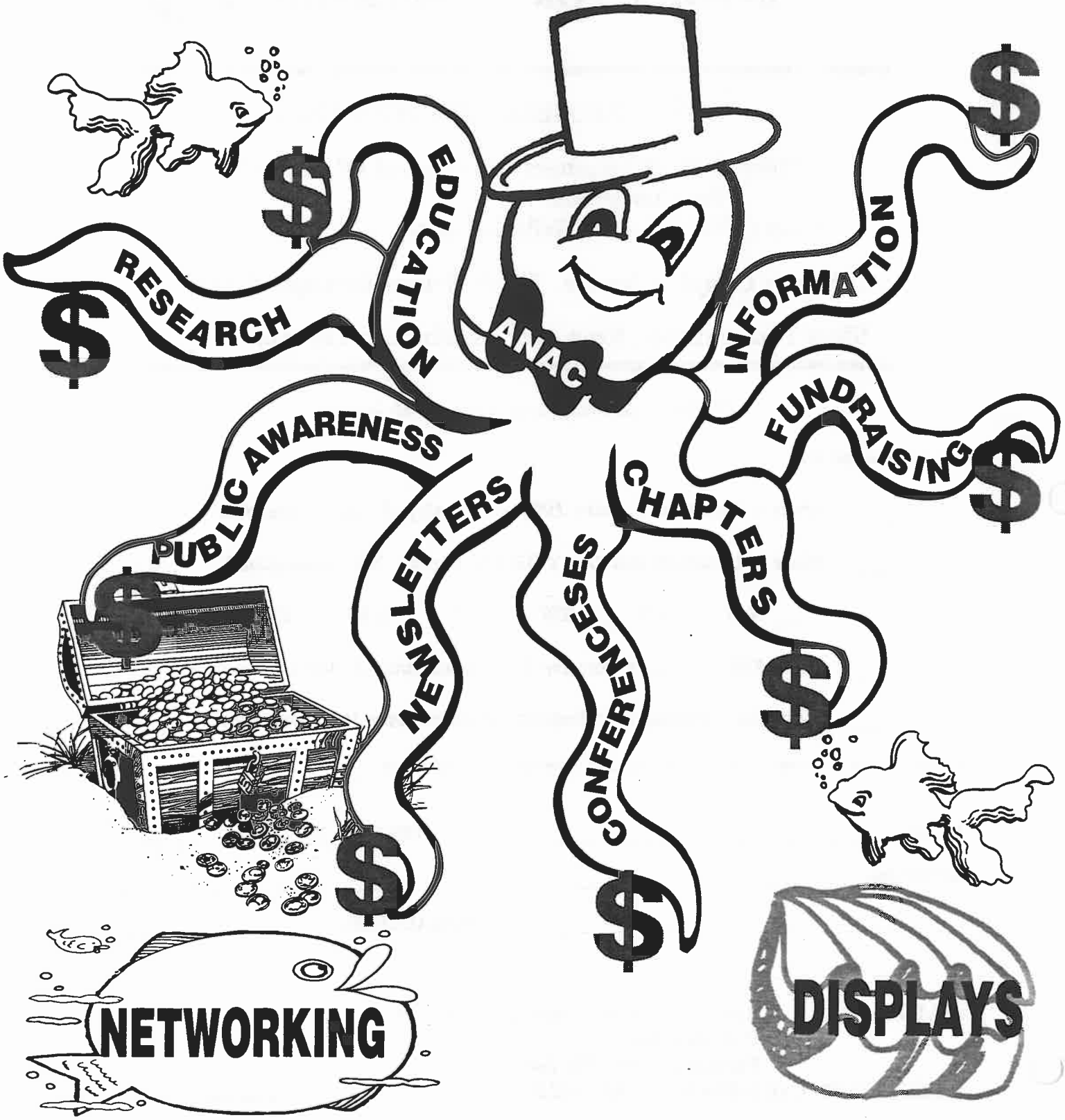

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... T.E.A.M.

Acoustic Neuroma

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News and Views from the Chapters

August, 1995

***Chapter News** is filled by the contacts with local 'news and views'. Your comments and suggestions are important to us.*

British Columbia

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Vancouver BC V6K 1H3
604-736-1215
Vancouver Chapter President

* Harry Kraeker
#306-1655 Chambers St.
Victoria BC
V8T 3J7
604-384-7530
Victoria Chapter contact

Report from Evalyn:

Before going any further...on my way home from the AN meeting in Victoria I was behind a car with the following bumper sticker: *Tinnitus Sufferers Know No Silence*. I'm curious to know who/where it came from. Has anyone else seen it??

The annual Vancouver Island AN meeting was held on April 8.

Eighteen people attended the lunch and heard Barbara Hooker of Prince George present her project recently completed and presented to a nursing class at University of Victoria. After receiving responses from a questionnaire sent to ANAC members in BC, she compiled a booklet entitled *'Acoustic Neuroma, The Hospital Experience, for Patients and Families'*.

Congratulations, Barbara on an excellent booklet, and on obtaining your BSc in Nursing.

Barbara would like people in the Prince George area to contact her. She is anxious to start a local support group.

Wenda Deane, who travelled from Vancouver for the meeting, informed us of the planning committee's accomplishments for the upcoming 1996 Vancouver Symposium. It's one you don't want to miss - start planning now!

Draws, made for the raffle prizes, were won by people in Pt. Alberni, Sayward, Courtenay, and Tom Walton! Proceeds of $405 will be used to offset chapter expenses.

I am pleased to have received four letters from AN people who read about ANAC in their local newspaper. This is a result of me contacting 25 papers with a letter to publish.

I challenge members across Canada to write to newspapers in your area. It is simple and effective. Please contact me if you would like a copy of my letter as a sample.

--*-*-*-*

Alberta

* Verna Thoman
15216 63 St.
Edmonton AB T5A 4V7
403-456-5468
Edmonton contact

* Brenda Hutchinson
57-70 Beacham Way NW
Calgary AB T3K 1R8
403-295-2080
Calgary contact

Report from Verna:

The Edmonton Chapter enjoyed a wonderful time at Alberta Beach on Saturday, June 11th. Basking in 23 degree temperatures and watching wind surfers from the deck...what a life!

Conversation was as relaxed as the day. We talked about adjusting our lives after our AN's - and riding a bike again. We also talked over advantages of deafness on one side, joked about tuning out barking dogs, traffic noise and spouses, and talked about coping (one-sided hearing) when we are a driver or passenger in a vehicle.

The fun and laughter continued with the evening barbecue. Everyone left understanding and knowing ourselves and each other better.

Next get-together: a meeting at Grant MacEwan Community College (the new Downtown Campus), Tuesday October 10, 1995. See you then.

--*-*-*

Manitoba

* Leslie Sutherland
36 Valleyview Dr.
Winnipeg MB
R2Y 0R6
204-837-5280

Report from Leslie:

Editor: Welcome to Leslie who has volunteered as contact person for the Manitoba chapter of ANAC.

On Tuesday, May 30 about twenty people gathered for our last meeting of the season.

It was a special time to celebrate Doug Cullens' *Happy 71st Birthday* and expressed our thanks to him for being ANAC's Manitoba contact for the past several years.

During the meeting one member and spouse described their recent research into treatment for the remaining portion of their AN, and their subsequent trip to the US for gammaknife treatment. We also heard of one member's recent surgery to take a nerve from her leg and place it in her face. This will hopefully regenerate and give back some facial movement.

Our group consists of pre and post-surgical patients, friends and family members, and represents a variety of benign brain tumors, the majority being ANs. Although the tumors are all different, the problems faced by patients and families after surgery are similar. Those who have been through it often have practical insights for those currently facing surgery and recovery.

Next meeting: Tuesday, Aug 29 St. Boniface Hospital.

The meeting schedule will be available at that time.

--*-*-*

Ontario

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* Cor Verbeek
  126 Ashley Cres.
  London ON N6E 3P8
  519-681-1719
London Contact

* Frank Fusca
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  Scarborough ON M1W 1J2
  416-495-8979 TDD
National NF2 Contact

Report from Barry:

The Toronto Chapter is looking to hold a meeting with a speaker in the month of October. The planning has begun and an announcement letter will be sent to all members prior to the date.

We are reorganizing the Ontario mailing list, so if you want to verify you are included on it, call ANAC national office at 1-800-561-ANAC.

If you have other questions please call Catherine or Barry.

--*-*-*-*

Nova Scotia

* Anna Parkinson
  52 Auburn Ave
  Halifax B3R 1K5
  902-477-2396 TDD
Nova Scotia Chapter contact for Acoustic Neuroma & Late Deafened Adults Support Group

Report from Ed Morrisey:

In this issue I am reporting on three meetings...**March:** a fun time was spent learning to paint! Thanks Peggy, and we hope you will do it again. **April:** A big thanks to Lindsay Oss, one of the guests, who discussed his AN surgery of Feb/95 in Montreal. There was much interest and lots of questions for him. **May:** Frank Hubley, ANAC member, spoke of his extensive research (esp. Gammaknife) for treatment of his AN. It was enlightening, and the answer truly is early detection.

New toll-free nos. in NS for MT&T special needs centre is 487-5553 voice; 487-5999TDD.

Thanks for all United Way donations, they have been received.

Anna Parkinson has a supply of buttons: *'Speak Slowly, I Only Read Lips'* for handout. They were donated by Dennis Herx.

Remember, the task of our Group is support: tell us of speakers or topics of interest, meeting ideas, anyone sick or lonely, concerns of yours, etc.

A complete copy of ANAC's national program EAPAN is available upon request. It is felt ANAC deserves our support of this project.

Thanks to all who contributed to the ticket sale on behalf of the Society of Deaf and Hard of Hearing NS. Proceeds will cover expenses of hiring a note-taker

for the lap-top computer.

Remember, save Sobey and IGA cash register slips to pass on to Dave Spencer.

On May 31, David and Peggy attended a breakfast meeting concerning disabilities. The Fisheries Minister for NS was seated at their table and was impressed to hear of our lap-top computer and panel enabling everyone to read & participate. Part of the meeting discussed aids in the workplace, and note-takers similar to Jane's typing were present.

--*-*-*-*

Quebec

* Marie Legault
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National Director/Quebec City contact

* Marie Catherine Lescouflair
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  514-682-8680
Francophone Contact

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

Report from Marie Catherine:

Over 40 people attended the Apr 30 meeting. Dr. Schondorf, neurologist, gave a well-informed talk on headaches and AN.

Because of ANAC's 'cross-Canada networking, a Montreal member, who also has MS, has made contact with a member in another province with similar problems. Thanks to everyone who worked on making this contact possible.

1996 Entertainment Books will soon be here...call Shirley, Romas or Marie Catherine to put in your order. The profits will be used toward chapter expenses & activities.

Montreal Chapter is eager to start EAPAN's pilot project. Anyone interested or with questions call Romas, Marie Catherine or Shirley. It is a great opportunity to learn how you can help in the publicity of AN information - there is a place for everyone!

Several local members attended the 3rd Annual Brain Tumor Information Day in June. The speakers were informative, one being a notary who answered questions of legal concerns. The afternoon included work-shops.

...Keep in touch, we look forward to hearing from you.

--*-*-*-*

National Office, Edmonton

Report from Linda Gray, Office Manager:

Jan Stuckey, employed with ANAC's office for over 7 yrs, recently resigned for personal and health reasons. She is missed greatly in the office, but will stay active in ANAC as the Treasurer on Board of Directors.

Welcome to Michelle Rurka who joins Verna & I in the office one day a week. Her interest in ANAC brings added enthusiasm to the TEAM.

My apologies for the lateness of this newsletter issue, there are only so many hours in the day...it is worth waiting for though!

Thanks for keeping in touch with ideas, hints and new medical papers. They are passed on whenever appropriate.

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,

I am interested in hearing from anyone with no change in tumor size, like me, and who has been following it without needing surgery yet. When is the proper time for any decision?

Ann Matte
22 Laverendrye Cr.
P.O.Box 291
Marathon ON
P0T 2E0

Dear ANAC,

My husband and I have an apartment in Dunedin, Florida, which we hope to let to anyone visiting Florida in the January - April period (preferably for approx. 3-4 months). If you have 'Snowbirds' in your membership interested in this, please put them in touch. The apartment has two bedrooms, two bathrooms, etc. It is sea-front, and ground floor, near to the swimming pool.

Sue Clifford
Membership Chairman, British ANA
22a Lambley Lane
Burton Joyce
Nottingham England
NG14 5BG

Dear Editor,

Ages ago I read an advertisement for 'Nozovent'. It helps breathing at night and stops snoring. I thought it worth trying as Tom says I have snored since the operation.

In my usual fashion I did nothing about it until I saw a letter in the Canadian newsletter about it. That spurred me to buy one. I tried it last night. It's a little uncomfortable to start or it was for me, I have a smallish nose, but I slept well and woke this morning feeling better than I have for a long time. My brain even feels it is working.

I had always gone to sleep on my good side, holding my face so the nostrils were clear but the hold would relax when I was asleep and all I got were a few more creases on my face.

Peggy Procter
29 Douglas St.
Rosanna 2084, Australia

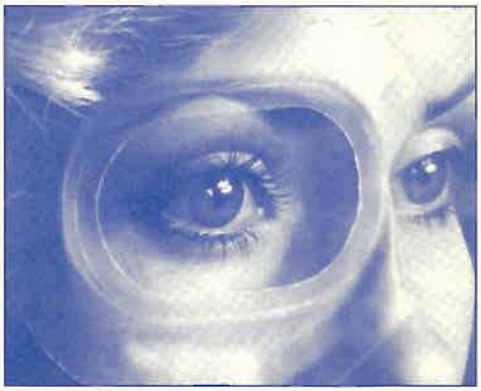
(Reprinted from AN, Network, Australia)

ANAC Purchasing Guibor Bandage Supply in August - Order Now

The Guibor Bandage, bubble or flat, is "a self-adhesive dressing with clear dome window that applies in seconds. It supplies an airtight moist chamber for dry eye syndrome or seventh nerve palsy. Also protects eyes during anaesthesia and as post-operative dressing. The flat bandage is specially designed with a flat, clear window for those who wear eye-glasses."

ANAC will be ordering in August and we expect to be processing your order in October. Cost is $30/pkg of 10 with payment when you order. Your cheque will be held until product is mailed to you.

Call Now: 1-800-561-ANAC; or write: ANAC, Box 369, Edmonton AB T5J 2J6.

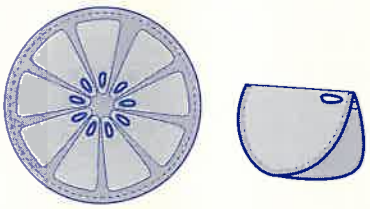


The Lemonade Stand

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.

What helped you after your acoustic neuroma treatment? Perhaps it is still a help...are you willing to share it with others? Send it to The Lemonade Stand - it may be just the recipe someone's been looking for!



Recipe 1: 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.

Recipe 2: It takes time to adapt to surgery deficits. Be easy on yourself. Perfection is unattainable, so learn to enjoy the imperfect YOU - it's more fun!

Recipe 3: 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.

Recipe 4: Be mindful of your general health. See a physician regularly for a medical and see a dentist and ophthalmologist routinely.

Sound Familiar?

by Tom Riglar

Tom Riglar, one of ANAC's national Directors active in the area of fundraising, is also an enthusiastic supporter of chapter activities, previously in Montreal and now in Vancouver - his latest commitment being the 1996 Symposium Planning Committee. His story capably demonstrates the importance of enjoying the humor in situations.

At our 1994 Annual General Meeting in Edmonton, Linda Gray and I were satisfying our carnivorous habit at the Rib Restaurant just down the road from our main meeting place. Between mouthfuls of these delectable goodies and large swallows of the local draft beer, I managed to tell and she managed to understand the following story concerning my Acoustic Neuroma. After all what goes better with beer, ribs and good company than a few laughs!

In one of my former lives I worked for National Trust in Montreal and had a staff of some fifteen people. We took care of Company pension plans and other corporate financial arrangements. Our group worked closely and had become an efficient team over the five years together. One day I began to get a rushing sound in my ears and did the customary rounds of doctors and tests. **Sound familiar?**

Several hours after my diagnosis I called everyone into my office and explained to them what was going on. At this point the rumours had been rampant about Tom's brain tumor, his eventual demise and in typical mega-corporation style, the upcoming race for his replacement.

I was scheduled for surgery in 5 days. I visited all my old friends and ate and drank like a pig just in case I didn't make it. The 2 short weeks I originally thought I'd be off turned into a bit longer but after about 2 months completely off and 6 weeks of mornings only, I was back. **Sound familiar?**

In one of his other lives, Tom Riglar is a large bunny rabbit for the Variety Club of BC and their Special Children.

My balance became better each day, my head hurt and my eye needed lubricant but damn it, I could do it. Everyone up and down the corporate pyramid gave me encouragement - because I told them exactly what had happened. If people don't know what's wrong with you they don't know how to react to the situation. As soon as you make them feel comfortable they are fine. **Sound familiar?**

Over the next several years, the people associated with me, both at work and away, knew of my involvement with The Acoustic Neuroma Association of Canada. My secretary pledged her time to assist us in every way possible. My immediate superior gave me time off for important events. The Mortgage Department even supplied the paper and pens for our 1993 Symposium in Montreal.

There was little turnover in the department but a few babies and relocations necessitated several new hirings. Through diligent and persistent searching we managed to get some great talent. One such person was a girl I will call Renee (because that was her name!). She was bright, aggressive and curious as well as knowing a great deal about RRSPs! We continued to have our weekly department meetings and my acoustic neuroma was mentioned now and again.

After one such get-together, about a month after Renee joined us, she showed up at my office door asking to speak to me. As I take these situations very seriously I offered her a chair, closed the door and informed my secretary that we were not to be disturbed.

Renee began, "I don't want to embarrass you but I just have to ask."

"Go ahead," I answered, remembering that she had been hired because she was bright, aggressive and curious.

"Well, there's just something I have to know," she said, "...what was the thing you had before I joined the company?"

"Oh, you must mean my acoustic neuroma," I explained, "That's right, you weren't here."

Before I could elaborate, she interjected, "Yes, that's it...is that some kind of musical instrument?"

She was taken aback by my loud laughter but after my explanation and customary distribution of printed material, we both had a good laugh. She and I knew she had finally become an integral part of the group.

Thank You, Renee for giving me a chuckle which will last at least one lifetime.

Editor's Note: We have heard many definitions of acoustic neuroma, but this is the first with a musical tone. Tom also has a challenge for our readers, "I think we should encourage our members to send anecdotes connected to their own particular situations - laughter is the best medicine....along with ribs, beer and good company!" Can you match this one? Write it down and mail it quick - we need more chuckles.

EAPAN: An Important Title For An Important Program

EAPAN or Education and Awareness Program for Acoustic Neuroma is designed to strengthen and promote ANAC's purposes, objectives and progressive attitude. Dedicated ambassadors, trained and educated as volunteer spokespeople for EAPAN, will extend ANAC's public profile, and increase support of and commitment to it.

To What Purpose?

"To improve public awareness and to further expand the Acoustic Neuroma Association of Canada by training volunteers to become ANAC representatives and spokespeople for personal fundraising and disseminating information and literature to the media, at public and health-oriented conferences and meetings, and in private settings. Through medical and general media publicity, EAPAN will reach thousands of Canadians each year with information about acoustic neuroma." - the EAPAN Purpose Statement

Tell Me More!

It's starting in Montreal, right now, with the Pilot Project. The Montreal Chapter is eagerly planning Communication/ Equipping workshops to give spokespeople the materials and training to fit their engagement needs. Instructors will include facilitators, trained volunteers, specialized professionals (areas of medicine, business, fundraising, legal and counselling).

A written report will be presented at the Vancouver Symposium, 1996. The Program will be assessed and revised for the expansion to the rest of Canada which will continue to occur as time and money permit.

It sounds like a Win-Win situation!

Yes, indeed. Benefits include: Volunteers' confidence & enthusiasm; Public relations & promotion of ANAC; Public awareness of AN; Improved information access; Local networking creating strong local units; Larger donor base due to an increase in awareness of the seriousness of undetected AN; Increased awareness of facial neuromuscular retraining; Treatment option awareness.

Spokespeople will include volunteer participants from the ANAC Boards (Directors & Medical Advisors), ANAC members, family members, interested parties connected to ANAC, financially supportive corporations & individuals; medical & business professionals; athletes/celebrities where appropriate.

They will reach the community of health professionals; diagnosed AN patients; the general public; people suffering symptoms suspicious of a potential tumor; potential donors (corporate & individual).

Where Will The Training Be Used?

Take a deep breath - it's an exciting and impressive list!

*1-on-1 conversations (hosp. visits, phone calls, etc.) *Media: radio/TV talkshows & health programs, writing & submitting articles for newspapers & magazines *Hospitals: medical rounds, inservice workshops * Service clubs Corporations, foundations & potential personal donors *Conferences: medical, charitable and public Schools/universities/colleges Associated not-for-profit groups Community meetings *Events (fundraising, etc.) *Industrial employee health service clinics *Churches Libraries: public programs *Displays (medical, public, associated not-for-profit groups).

So, How Can I Become Involved?

In the Montreal area, call Marie-Catherine Lescouflair, Romas Staskevicius, Shirley Entis or Jon Kantor and sign on to the local team. People from all walks of life and areas of expertise are needed. Your enthusiasm and support for reaching ANAC's mission, 'Early Recognition & Treatment', is an important asset for being an EAPAN spokesperson.

In other parts of Canada, submissions of potential spokespeople locally can be forwarded to a local Board member, or the national office toll-free at 1-800-561-ANAC.

As well, interest and expertise in specific areas are needed for the development of information materials such as specific issue brochures, video: symptoms, diagnosis, etc. (update of present one), posters for displays and handouts, conference materials (theme/group specific), and questionnaire evaluation form.

Chapters and contact people will be kept informed of the developments of EAPAN and will pass the information along locally. As well, the Connection will publish articles in each issue regarding the progress and volunteers needed.

I'm Impressed! Sign Me Up, Keep Me Informed and Train Me To 'Talk the Talk'! And I Challenge the Rest of the ANAC World to Join Me.

Symposium Update

Vancouver Chapter presents

FROM the PATIENTS POINT of VIEW

Treatment Options: Surgery? GammaKnife?

Dr. Michael McDermott, neurosurgeon, who formerly practiced neurosurgery at Vancouver (General) Hospital in Vancouver BC and now practices at University of California at San Francisco, and who has experience with both traditional surgical approaches and stereotactic radiosurgery, will speak on the treatment of acoustic neuroma.

...See You At The Symposium, May 31-June 2, 1996, Vancouver BC

For further information contact:
Wenda Deane
Pres. Vanc. Chapter
T26-888 Beach Ave.
Vancouver, BC V6Z 2P9
604-685-1014

Special Thanks to Our Contributors

March 1, 1995 to June 30, 1995

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. Gift amounts are never disclosed.

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Health and Welfare Canada — Santé et Bien-être social Canada

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

Enclosed ❑ $28 – 1995 membership
❑ $200 life membership
❑ _____ donation

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

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

Comments: _____

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A National Network of Contacts

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