

# the Connection

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PLEASE DO NOT REMOVE

## Acoustic Neuroma and Memory Problems

Deirdre Dawson, M.Sc., OT(R) is an Assistant Professor at the University of Toronto, and a Research Clinician in Occupational Therapy Services, Sunnybrook Health Science Centre, Toronto. Her major focus, clinically and academically, is related to outcomes following traumatic brain injury. In addition, she has a special interest in cognitive difficulties related to a variety of disorders including acoustic neuroma.

I have had a long-standing interest in memory difficulties related to brain injuries, but hadn't been aware that people who had acoustic neuromas (AN) also experienced them. A thorough search of medical and allied health publications in the last ten years produced nothing linking ANs with memory problems. It seems the parts of the brain affected by ANs are not known to be associated with memory difficulties.

Nevertheless, as many of you are aware, memory problems are real and can interfere significantly with day-to-day life. In this article I describe the memory system and explain how ANs might interfere with the memory process. I also provide suggestions for improving day-to-day function when a memory problem exists.

Those who experience memory problems know that so-called minor memory difficulties can cause both frustration and major problems in daily life. Such problems relate mostly to recent events. For example, high school graduation memories are clear, but the item to be retrieved from the basement is forgotten halfway down the stairs. Barbara Kristaponis<sup>2</sup> described looking at a message written the night before on her



telephone pad, seeing the name and number, yet having no idea to what it referred.

It is often difficult for others to

appreciate the reality of this kind of memory problem. When such problems are described, the response can be "Oh, I do that all the time." Educating family and friends about the nature and extent of difficulties should sensitize them and ultimately be personally helpful as well.

### How does memory work?

To understand memory problems, it is helpful to understand how memory usually works. The four main phases in the memory process are attention, encoding, storage, retrieval.

### Phase 1: Attention

Attention is divided into four types: 1) focusing and sustaining a consistent response over a period of time, such as when reading a book; 2) selectively focusing on one stimuli even when there are distractions; for example, carrying on a conversation at a party, or listening to someone on the phone when the radio is playing in the background; 3) alternating or switching attention from one task to another; for example, moving from the task at hand to answer the telephone and then returning to the original task; 4) dividing attention in order to do multiple tasks simultaneously; for example, driving a car while having a conversation.

To date, there is little evidence to support the idea that ANs interfere with the attentional and memory anatomical structures. However, recently Dr. Robert Frazier, neuropsychologist, and Dr. Kenneth Erickson, physician, have theorized that the vestibular system and brainstem, both of which may be affected following AN surgery are important structures for memory and learning. Their articles explain these theories in more detail<sup>3,4</sup>.

However, there are factors associated with ANs that may interfere with the attentional mechanisms and subsequently cause memory difficulties. These include loss of hearing, balance problems, pain, depression and fatigue.

Loss of hearing associated with AN removal means the attention system has to adapt to receiving less information of one kind (auditory) and work extra hard to obtain the necessary information in other ways. At least initially the attentional system cannot function as well as pre-operatively and the first phase of memory will be affected.

Balance problems may interfere in  
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Acoustic Neuroma  
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Your comments, ideas, suggestions and financial support are needed and welcome.

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## AN and Memory Problems

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a similar manner. The additional effort needed to maintain balance may hinder one's ability to attend to information in the environment. The other phases of the memory system build on these attentional mechanisms and thus, if attention is disrupted, memory may also be compromised.

Pain, depression and fatigue have all been documented by researchers as interfering with attention and memory. Information processing becomes more difficult when these factors are present. In turn, when information processing is more difficult, additional mental energy is required resulting in even more fatigue - a vicious cycle can ensue.

### Phase 2,3,4: Encoding, Storage, Retrieval

Encoding, Storage and Retrieval build on attention. The conveyor belt analogy of memory may help to understand this. When attending to something, it is put on the conveyor belt and only then can that detail or piece of information move along to be encoded, stored and later retrieved. If the information is not put

on the conveyor belt due to attention problems, the other parts of memory will be affected as they are not obtaining that information.

Encoding is the initial registration and recording of information. This registration is temporary at first, but later it becomes permanent and the information is stored. The process or permanent storage is assisted by rehearsal and organization of information. Retrieval refers to our ability to recover memories that have been stored.

### I have a memory problem - what should I do?

There are four issues I want to address in relation to dealing with memory problems: 1) ways of improving attention; 2) direct memory retraining; 3) compensatory strategies for memory problems; and 4) professional input. More details about some of these strategies can be found in the book, **Cognitive Rehabilitation of Memory: A Practical Guide**<sup>5</sup>.

### Improving Attention

Paying attention is hard work and, as I've mentioned, some of the factors associated with ANs make it harder.

Reducing distractions, such as background noises, will assist and lessen the demand on the attentional system; for example, turning off the radio, TV, and/or stereo while doing other activities like reading, baking, or having a conversation. Some people have found quieter restaurants and socializing in smaller groups assists their ability to attend and remember the event.

Fatigue and depression can be thought of as internal distracters. Reducing fatigue is another way of assisting attention. The sample schedule shown in Figure 1 helps identify how fatigue impacts memory.

Figure 1 shows that while preparing lunch, this person could not remember why Sue called. Using an answering machine would have allowed her to keep track of Sue's call and return it when there were no distractions. Figure 1 also shows that this person lessened her fatigue by selecting a sedentary activity (reading the newspaper) after taking her children to school. Someone else might decide to nap, listen to music or watch TV - something requiring less selective and alternating attention.

Analyzing your own schedule could be equally revealing. You, like

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## ANAC's New President Welcomed



Shirley Entis

by Virginia Garossino

After 11 years as President of ANAC, I am pleased to welcome Shirley Entis of Montreal as our second President.

Shirley has been an active member in the Montreal Chapter since she joined the Association in 1985. As a neuroscience nurse at the Jewish General Hospital in Montreal, she works closely with neurosurgeons, especially Medical Advisory Board member, Dr. Gérard Mohr.

She is dedicated to the support, research, information and communication that ANAC provides and is instrumental in promoting the Association to new patients she sees. She has been a key resource and volunteer in establishing the Rosanne Rosen Memorial Fund of ANAC and the 1990 Montreal Symposium. The Memorial Fund donates to the Facial Nerve Program at JGH which is manned by a multi-disciplinary team of voluntary medical professionals. It has been in existence for six years and has helped many people suffering facial palsies from many different

causes, acoustic neuroma being a major one.

As Vice President, Shirley spent the past year learning the business side of ANAC, and in her Presidency plans to continue expanding and building on the work already being done. She says, "We have an enthusiastic, dedicated Board with the skills and motivation to continue promoting ANAC's slogan 'The Hope Is Recognition & Treatment.' With improved communication, growing membership, and ever-increasing information, I look forward to the future of ANAC."

Under Shirley's capable guidance, we can expect continued program delivery and positive developments in the Acoustic Neuroma Association of Canada.



## AN and Memory Problems

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this person, might observe that you are more forgetful at times of the day when you are more fatigued. At those times rest periods and/or tasks requiring less energy and attention can be planned.

### Compensatory Strategies

Internal and external compensatory strategies can be useful for addressing memory difficulties. Repetition, or rehearsal of information, is the most important internal strategy. For example, when you need the screwdriver from the basement repeat "Get screwdriver,"

daily planner and a notepad beside each telephone are helpful to remember appointments. Check them as soon as you start your day and refer back regularly throughout the day.

Irons that switch off automatically, buzzers in the car to warn of lights left on, and watch alarms set to remind the wearer of a specific task are other aids. Documentation, as in Figure 1, can help determine what is needed.

### Direct Memory Retraining

Direct memory retraining programs need to be individually designed, a task normally done by neuropsychologists and/or

analysis of the specific difficulties in the context of the person's daily life and environment. Occupational therapists (OT) learn about attention and memory difficulties in their university programs. They learn how to analyze these memory problems and how to work with clients and their families. They also learn how to design strategies to help compensate for memory loss. OT's can be contacted through your local homecare association and/or OT department.

### Summary

The ultimate goal in dealing with a memory problem is to make it easier to accomplish daily activities and to enhance overall quality of life. The difficulties may be made easier by implementing some of the strategies suggested in this article, by seeking professional assistance, and by making them known to family and friends.

### References:

- <sup>1</sup> Dawson, D. (1994). Tricks for better recall: Overcoming memory problems after a brain injury. *Abilities, Summer*, 23.
- <sup>2</sup> Kristaponis, B. (1993). A purely personal report on memory and acoustic neuroma. *Voyages*, 8, 1, 3-4.
- <sup>3</sup> Erickson, K. T-3: *Cognitive aspects of vestibular disorder*. (Available from Vestibular Disorders Association, P.O.Box 4467, Portland, Oregon, 97208-4467).
- <sup>4</sup> Frazier, R. *Acoustic neuroma depression and memory deficits*. (Available from Acoustic Neuroma Association, P.O.Box 12402, Atlanta, Georgia, 30355).
- <sup>5</sup> Harrell, M., Parenté, F., Bellingrath, E., & Liscia, K. (1992). *Cognitive rehabilitation of memory: A practical guide*. Gaithersburg, Maryland: Aspen.

**Figure 1: Example of activity/fatigue/memory schedule**

| TIME    | ACTIVITY                  | FATIGUE LEVEL:                   | MEMORY PROBLEM<br>(describe)                              |
|---------|---------------------------|----------------------------------|---|
|         |                           | Score 0-5<br>(0=none; 5=extreme) |   |
| 12 noon | Lunch preparation         | 3                                | Sue called, after I hung up I realized I'd forgotten why. |
| 1 pm    | Drove kids back to school | 3                                | Forgot to go to dry cleaners on way home.                 |
| 2 pm    | Reading newspaper         | 2                                | None.   |

to yourself while walking down the stairs. In conversation, repeat back to people what they have said, such as "Great, so we're going to meet at Sue's place this afternoon at 3." Repetition helps transfer this information from a temporary to more permanently stored state.

Writing things down is the most important external strategy. The key is consistent use so you rely on your notes rather than your memory. A

occupational therapists. However, their effectiveness is questionable, and, in the case of AN, it is unlikely they would have any benefit, as there is no clear evidence for an anatomical basis to the memory problems being experienced.

### Professional Input

Selecting the best strategies and devices to assist with anyone's memory difficulties requires careful

## Bilateral Link

by Frank Fusca

Some people have told me they enjoy some of the little stories that have appeared here from time to time. Thank you for your comments and here are some littler stories!

### Before Deafness:

The night before my first AN operation the nurse came with a bottle. "It's a special shampoo" she said, "I have to wash your hair for the operation tomorrow." She tried to explain but the puzzled look had now become fearful. "Oh, don't worry,"

she went on calmly, "just a tiny bit of hair, no one will ever notice."

About a week after that tiny bit of hair went missing, I was still unable to go to the bathroom. The nurses were kind and would wash my face at the bedside. I've always had oily skin and at the time I was just getting over the highschool blemishes. I could feel myself breaking out again. One day, one of the more mature nurses was performing the task. "My God," she said when she had finished, "with skin like this, you will never get old!" I was 20 then, I'm 36 now.

### After Deafness:

I work in the heart of downtown Toronto. This is OK but when I

became deaf, I had to re-learn how to handle being approached by the odd street bum. I was caught by surprise early one morning. A person came up to me after exiting the subway and said something. I thought he was asking for directions. "I'm deaf," I said, "I don't understand. Can you repeat?" I watched as he pondered the problem. His eyes lit up when the idea popped into his head. He rubbed his thumb and forefinger together and said 'm-o-n-e-y.' I walked away but later realized that I owed him something. The effort made to communicate was priceless.

# ANAC Honors Its Founding President



**Virginia Garossino**

The 1994 Annual General Meeting held October 28, 1994 in Edmonton, was an ideal place to extend recognition to Virginia Garossino, founding president of ANAC. Her contribution to the Association was appropriately recognized by the establishment of the Virginia Garossino Fund.

The Fund will be used for projects pertaining to facial neuromuscular retraining. The announcement of the Fund was a total surprise to Virginia

and we were pleased to tell her that approximately \$2000 had already been donated by members, doctors, corporations and friends. She expressed what a great honor it is to have her work acknowledged in this way.

Virginia's outstanding initiative and leadership helped the Association develop into a national, aggressive and effective group. Earlier diagnosis is now happening, greater public and professional awareness is a fact, and facial neuromuscular retraining is now available in many parts of the country because of her vision and determination.

Along with Virginia, Velma Campbell and Linda Gray were appropriately honoured for their exceptional leadership and work, with gifts of appreciation presented by Shirley Entis and Jan Stuckey. Hand-crafted albums filled with letters and notes of commendation from members across Canada, as well as crystal oysters containing a pearl and placed on engraved mirrors, were meaningful and personal gifts.

In accepting the recognition, they expressed their appreciation for the

support received from the Medical Advisory Board, members, media and the business community over the years. They also noted how gratifying it is to see the work of the organization carry on under new and very capable leadership. They will remain involved: Virginia as past president, Velma in the Edmonton Chapter activities, and Linda as office manager in the National Office.

If you would like to acknowledge their contributions to the Association and show your personal appreciation to our founders by way of a card, letter and/or donation, your mail will be directed to them through the National Office.

## *Virginia Garossino Fund*

*Founder and President  
of the  
Acoustic Neuroma Association  
of Canada*

*October 29, 1994*

## AGM Weekend A Busy One In Edmonton

Nine of ANAC's Directors met in Edmonton, October 29 & 30 for a Board of Directors Meeting held in conjunction with the Annual General Meeting. Those were: Virginia Garossino, Shirley Entis, Linda Gray, Sharron Foster, Velma Campbell, Jonathan Kantor, Tom Riglar, Susan Rankin, Jackie Diels. Irma Arnold and Marie Legault, who accepted Directorships just prior to the meeting, were not in attendance.

The agenda was extensive. Saturday morning, Ed Brownfield of E.E. Brownfield Management Consultants, facilitated a follow-up session for Strategy Planning. The 1992 meeting was revisited and examined, with emphasis put on 'where ANAC is headed now.' It was encouraging to see that the 1992 plan is being implemented and that changes are in progress.

The afternoon session centred on the issue of fundraising. Due to

forthcoming changes in the federal government's sustaining grant program, private contributions are even more important now. Jonathan Kantor, Director of Fundraising, emphasized yet again the importance of member involvement, personal contacts and successful promotion of ANAC's financial needs.

The Annual General Meeting was attended by approximately 30 people. Virginia Garossino announced there would be a new slate for the election of officers as she, Velma Campbell and Linda Gray stepped down from their positions as founding directors.

It is a pleasure to announce the newly elected officers: Shirley Entis, President; Jonathan Kantor, Vice-President; Susan Rankin, Secretary; Sharron Foster, Treasurer. They are committed and eager to continue the work of ANAC, especially in the areas of communication, support and

information to members and new patients, as well as inquiries from the medical community and the general public. Each has spent time on the Board prior to their present positions - Shirley as Vice-President, Jon and Susan as Directors-at-Large, and Sharron as interim Treasurer.

Presentations to the founding directors followed the formal meeting and the evening ended with a special cake, coffee and camaraderie.

The Board's Sunday morning session completed the weekend agenda, with discussion of projects and activities for the coming year. Items included the 1996 Vancouver Symposium & Facial Neuromuscular Retraining Workshop, chapter development, and cross Canada communication.

It looks like a busy and productive year ahead.

# *News and Views from the Chapters*

December, 1994

*Chapter News has lots of room for local 'news and views'. Feel free to forward information to your local contact so he/she will add it to the info being gathered. Your comments and suggestions are important.*

## ***British Columbia***

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\* Wenda Deane  
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604-736-1215  
Vancouver Chapter President

### ***Report from Wenda:***

At our September meeting we were pleased to present Peggy Bray with flowers and a silver tray in appreciation of all her hard work as Contact Person for the past 5 years.

We were also honored that Virginia Garossino was able to be present for this part of the meeting.

There was much discussion regarding the forthcoming Symposium, and information about it will be given in the 'Symposium Box' in this issue and each of the future ones up to the time of the event.

The Chapter has made application for a grant and will make application for a

casino license in order to raise funds. Tom Riglar spoke about and distributed Entertainment '95 books, the proceeds of which will be used towards the symposium costs. Anyone wishing to purchase a book, please contact Tom at 604-734-3621 (home). They are excellent gifts for any occasion.

We adjourned for coffee and birthday cake in honor of the 80th birthday of long time member Stan Biloes, and the 70th birthday of Dorothy Shuck who, unfortunately, was unable to attend.

### ***Report from Evalyn:***

I am pleased and excited to report that Victoria had its first chapter meeting on Friday, November 25. Lorraine and John Thorliefson opened their home to 8 of us. It was a wonderful evening of getting to know each other and of sharing our AN experiences and tips on better coping.

Barb Hooker described her program at the University of Victoria, and presented her first draft of her booklet regarding hospital expectations of AN surgery, which is being developed for one of her courses.

It was agreed that the Victoria Chapter of ANAC will start up in the Spring of 1995.

\*\*\*\*\*



## *Alberta*

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\* Verna Thoman  
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### *Report from Verna:*

Our Edmonton Chapter had a wonderful Christmas party at my home on Tuesday, December 13th. The evening was filled with friendship and laughter.

We had a relaxed and casual discussion regarding future speakers and some excellent suggestions were tossed around. I'm sure we have exciting and rewarding times ahead.

Our Chapter wants to print a list of post-op problems and solutions for AN patients leaving the hospital. I would appreciate receiving your input regarding your experience and any helpful ideas you have.

We all had fun with our gift exchange -- some honest stealing went on but everybody went home happy!

Thanks to Linda Gray and Loretta Miller for bringing cake and cookies.

Our next meeting is tentatively set for early March, 1995; further information will follow.

## *Manitoba*

### *From the Editor:*

Doug Cullens recently expressed his intention to step down as Chapter Contact for Manitoba.

On behalf of ANAC, in particular the Winnipeg members, I take this opportunity to thank Doug for the years he has devoted to the position of Chapter contact.

We have appreciated the information he has forwarded for the Chapter News, as well as keeping us informed of new inquiries and members, their addresses, etc.

Doug is still interested in keeping in touch with friends he has met, so please give him a call from time to time. I am sure you will continue to see him at most meetings. He also can explain what is involved being the Contact person, so please give him a call if you are interested in replacing him.

Thanks again, Doug...many people have benefitted from your time as Manitoba contact.

Anyone interested in letting their name stand for new contact person, please call Linda at the ANAC office in Edmonton (1-800-561-2622).

The Brain Tumor Support Group meets at St. Boniface Hospital every 6 weeks.

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\*-\*-\*-\*-\*



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National Bilateral Contact

### *From the Editor:*

Season's Greetings and the  
Best in '95 from all the  
Contacts.

\*-\*-\*-\*-\*-\*



## *Quebec*

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Montreal Chapter Contact

### *Report from Montreal:*

From all the members of the  
Montreal Chapter we wish  
everyone the Best of this  
Holiday Season.

We look forward to continuing  
the interesting and informative  
networking in 1995 - whether it  
be at local meetings, chatting  
with someone on the telephone  
or meeting with others on an  
individual basis.

If you have a topic you would  
like to see presented at a  
local meeting, please let Marie  
Catherine, Romas or Shirley  
know of it so we can include it  
in a future.

Happy New Year.

\*-\*-\*-\*-\*-\*

*Happy Holidays*

*Happy New Year*

From Shirley Entis, the  
Board of Directors, and the  
Office Staff.

## *Nova Scotia*

\* Anna Parkinson

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

### *Report from Ed Morrissey:*

I trust this year has been 'an OK year' for you. As I sit before the computer the big chill is here and we expect lots of snow before it gets better. I always feel we, in this part of the world, are able to get the best of exercise...shovelling!

We had two very interesting talks at our October meeting. Patricia Jennex, Director of Lifeline and Telecare Services, is with Northwood Home Care, a non-profit home care group. She discussed a 'help device' which is worn on the wrist or around the neck. When someone is in difficulty he/she presses a button and assistance will be on the way. Another service in Dartmouth phones people living alone, every day to check on them. Call 902-454-3346 for more information.

Jamie MacDonald, Director for the Society of Deaf and Hard of Hearing Nova Scotia gave a brief overview of the Society and his function within it. He spoke of the need for more Sobey and IGA cashier slips to purchasing equipment. Please keep saving and bring them to David Spencer at the next meeting. The return is \$1/\$300 in receipts, so many are required. I understand this offer will not last much longer so the slips are required now.

Although Jane and Carmel have

left the executive, they are not leaving the Group. They will be attending the meetings and Jane will continue to be our note-taker.

In November Dr. Robert Hoar, prosthodontist spoke on the effects of AN and dental implications. It was a most informative and interesting talk. Many questions were answered, not only for AN people.

The December meeting is a social.

Just a reminder, if you know of someone you feel should be included in the Group please advise. Also, we are open for ideas for projects. Should you have any ideas let us know.

Next Meeting: Tuesday, Dec 13/94 7pm, Gerrard Hall, The Infirmary. Hope to see you there.

\*--\*--\*--\*--\*

## *National Office, Edmonton*

### *Report from Linda Gray, Office Manager:*

A Big Thank you from the Board and Staff to everyone who sent Christmas and Holiday greetings to the ANAC office. We wish you every happiness throughout the holidays.

...Talk with you in '95!





# *Acoustic Neuroma*

## *Information Available*

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# 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,

Many, many thanks for your very prompt response to my phone call and all the enclosures which have proven most helpful.

From the contact list you sent, I had already spoken with Barry as he was in a help group with me at Sunnybrook. I shall be contacting the two ladies listed - thanks.

Appreciated viewing the video and am returning it herewith.

Haven't had an opportunity to do any further enquiries, but if I obtain information that I feel will be beneficial to the Association, I shall be happy to forward it on.

Sincerely appreciated speaking with you, Linda. You made me feel

quite good about my situation. Up to that point I had pretty well put it on a back burner (I guess hoping it would go away).

I have joined the Area Committee for the Canadian Hearing Society in Barrie and, once again, if I come across material that may be of interest to you, I shall forward it.

Eileen Hanafin  
R.R.#1  
Thornton ON  
L0L 2N0

★★★★

Dear ANAC,

Thank you for the information about CSF leaks, which I gave to my friend. She didn't have surgery, because after a few weeks, and a hospital stay, it cleared up on its own. She is still tired but I told her that only time can cure that; and the frustration she feels - we have all had that, and it will also go away.

What really helped me the most was to talk to and read about people who went through this. I'm really grateful to ANAC for this.

We were living in Holland when I had my first two operations (9 hours and 13 hours in 1985). When we moved to Canada I was put in touch with Dr. Nedzelski, Sunnybrook Health Science Centre, who did my last 9 hour operation and also the 7/12 nerve hookup. I am very grateful and satisfied with what he did. My tumor was 5cm.

We have since moved back to Holland because of my husband's health - the dust on our chicken farm gave him trouble breathing. He works here in demolition and we have settled down nicely again.

I am feeling fine and, as I told my friend, everyday you see an improvement. Always think positive - this also helps.

Thank you again for writing back.  
Angie Van Groningen  
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The Netherlands

## Update on Research

by Susan Rankin

In reviewing our strategic plan at the last Board meeting, we reviewed our purpose statements for the Association. There are four main reasons for ANAC to exist: 1) to provide **support** and information to people with acoustic neuromas and their families or friends; 2) to supply **information** to health care personnel; 3) to promote and support **research**; and, 4) to **alert** the public regarding symptoms.

This column is to update you on #3, research activities that ANAC is involved in promoting and supporting. In 1994 there have been three research projects of which you may be aware.

Ongoing from 1993 is the development of a facial grading system by Brenda Ross and Dr. Julian Nedzelski at Sunnybrook Health

Science Centre in Toronto. This research has important implications for facial rehabilitation and research. It provides an objective way of charting progress in facial recovery. This work is an excellent example of well-designed research as is previous work done by this team. Two of our Board members, Jackie Diels and Susan Rankin, have taken part as clinical assessors to determine the effectiveness of this tool. We eagerly await results and send our congratulations to Brenda Ross and Julian Nedzelski for their ongoing work in the area of facial rehabilitation. Thanks also to any ANAC members whose faces were videotaped for this project and to other clinical assessors.

Another project was carried out by Joe Anderson, a fellow acoustic neuroma patient in the United States. Many of you generously agreed to

participate in this research by completing several surveys. Joe's PhD thesis entitled "An investigation of the information-seeking behaviour of adults who have been diagnosed with a unilateral acoustic neuroma" compared acoustic neuroma patients who had stereotactic radiosurgery in the U.S. with Canadians who had microsurgery. I know some of you were disappointed that you were excluded from the study because your microsurgery was performed before radiosurgery was available, but exclusion criteria are a necessary step in research in order for it to be fair and unbiased. Questionnaires are often used in preliminary research like this one. A lot of information is gathered and usually more questions are generated that can lead to more specific research. Many thanks to all

*continued on page 6*



## Update on Research

continued from page 5

of you in supporting Joe Anderson's research.

So what did Joe find and what are the implications of this research? Joe wanted to find out if people facing uncertainty in illness fell into one of two groups with respect to how they sought information: those that avoided information or those that sought a lot of information. His results showed equal percentages of adults from the microsurgery group and the radiosurgery group avoided or sought more information. He then tried to narrow down which people seemed more likely to seek information based on gender, age, education, recommendations of consulting and referring physicians and other criteria. These results have implications for health care practitioners and educators in understanding the amount and type of information desired by individuals. In order for people to make the best, most informed decision about treatment choices, health care professionals must provide a good

environment for information to be obtained. The full results of Joe's research are available through the national office for anyone who is interested.

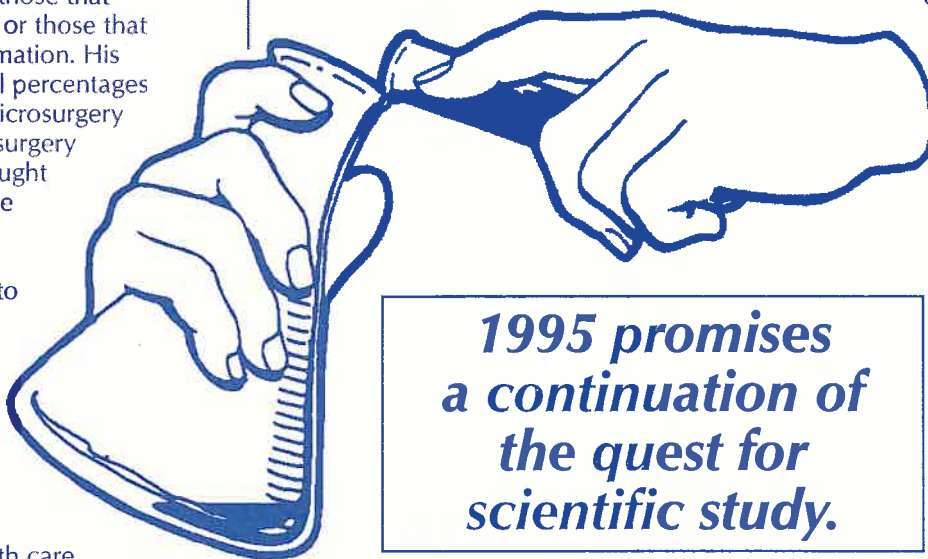
Another project, in which some BC members participated, was carried out by a fellow AN patient and Association member. Barb Hooker designed a questionnaire as part of a

helped clarify Association procedures with respect to participating in research. In supporting and promoting research we maintain confidentiality of our member lists and ensure that proposed projects will benefit our members in some way. We look forward to hearing about Barb's results and hope to see her on the neurosurgical floors some day providing quality and personal information to acoustic neuroma patients.

1995 promises a continuation of the quest for scientific study. A collaborative study centred in Montreal is looking at electrical stimulation for treating facial palsy. Implanted electrodes for continuous stimulation will be used mainly on people with cross facial nerve grafts and compared with a control group.

There may be other research projects in

other parts of Canada that have not been mentioned in this column. Please let the National Office know and we'll have other "Research Updates."



course for the Bachelor of Nursing programme at the University of Victoria. Like Joe Anderson's research, it addressed information acquisition prior to AN surgery by means of a short survey. Barb also

## 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!

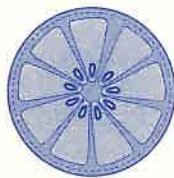
Recipe 1: An important tip to remember whenever you are a patient in the hospital - Make sure there is a sign above your bed announcing your deafness in one ear (be sure to identify which one).

Recipe 2: If we have no choice in what life serves us, then we may as

well make the best of the options we do have!

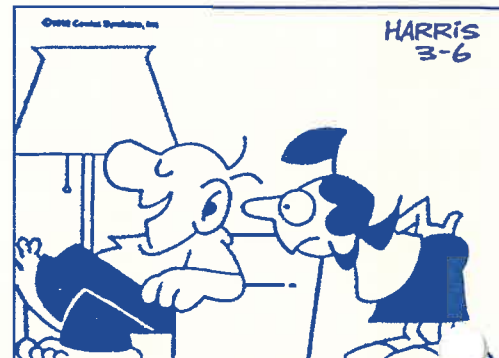
Recipe 3: A counsellor I had seen several years ago gave me some good advice and suggestions. She said, "Stay involved, take the initiative to meet others, but don't force yourself on them. Go for coffeekbreaks in small groups - small talk is important." (I found 1:1 is even better). Only years later did I realize the value of what others had been telling me.

Recipe 4: I have had a lot of back problems since my AN surgery, and the neurologist said that losing the balance nerve during surgery, results in not carrying ourselves straight.



Although I do not have a remedy, I feel it is important to alert others of this problem.

### THE BETTER HALF



**"It's a special type of hearing aid. It only lets you hear kind words and compliments!"**

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# Vancouver Hosts ANAC National Symposium

**Theme: 'From the  
Patient's Point of View'**

**June 21, 22 and  
23, 1996**

Welcome to the ANAC National Symposium Update. You'll be noticing that this **Update Box** will become a regular part of the *Connection* in the months leading up to the Symposium. We hope to use this opportunity to keep you posted and to request your input on preparations. As you can see the theme has been chosen. We hope this Symposium will be successful in addressing the issues that concern you and your families. So far, some of the topics being considered are:

- \* stereotactic radiosurgery
- \* short term memory loss
- \* humor
- \* value of a positive attitude

We are considering changing the format from addresses by medical and other personnel to one involving more member participation (eg. panels involving patients and roundtable discussions). The Vancouver Chapter requests your suggestions for speakers, structure, specific issues of concern or any other ideas for the Symposium.

Please send suggestions to:  
Wenda Deane, President,  
Vancouver Chapter, ANAC  
#26 - 888 Beach Avenue,  
Vancouver BC V6Z 2P9  
(604)685-1014

Thank you for your Input!  
Watch the Symposium take shape  
in the following issues of the  
*Connection*.

## Pre-symptomatic Testing For NF2

by Dr. Guy Rouleau

The gene responsible for neurofibromatosis type 2 (NF2), a disease which results in the development of bilateral acoustic neuromas as well as other brain tumors including schwannomas and meningiomas, has recently been isolated. Though we do not as yet know the function of the NF2 gene, nor how it leads to tumors, this discovery is important to patients with NF2. The disease is genetic in origin and so patients with NF2 have a 50% chance of transmitting the disease to their children. Furthermore, people who inherit the NF2 gene are almost certain to develop tumors sometime in their life. Absence of a family history of NF2 does not eliminate the diagnosis of this disease because 50% of cases just appear without any family history.

DNA tests can be used to confirm the diagnosis of NF2 and to determine if family members who are at risk for the disease have inherited the illness. Currently there are two types of DNA diagnostic tests available. The first involves linkage analysis which can only be performed when the disease is inherited and there are at least a few people affected with NF2. The test requires a detailed family tree and the cooperation of many members of the family.

The recent identification of the NF2 gene allows a second diagnostic test where the gene is looked at directly. The test can be done on anyone, regardless of family history. It can be used to confirm the diagnosis of NF2 and to determine if relatives of an NF2 patient have the disease, even before it starts. However, the current technology only allows the identification of the genetic abnormality in 50-60% of patients. It

is important for people to know whether or not they have inherited the NF2 gene because the disease may only manifest itself later in life and it is important to know whether or not an individual has a chance of developing the tumors.

The advantages of this test are that 1) at-risk individuals who do not have an NF2 mutation no longer need screening tests; and 2) at-risk individuals who have an NF2 mutation can be screened more closely so that tumors can be identified when they are quite small.

If an individual does carry the mutated NF2 gene, then he or she will require an enhanced MRI every second year with audiometric testing and a physical examination on a yearly basis. If an individual does not carry the mutated gene, then this screening process is not required.

Since we are very early in our knowledge of the responsible gene in NF2, no direct therapy is currently available. However, only with further research and cooperation from patients and their families will we ever be able to gain further knowledge into the mechanisms of how mutations in the NF2 gene lead to tumor formation and hopefully therapy in the future.

Anyone with the diagnosis of NF2, or who wants pre-symptomatic testing, is encouraged to submit a blood sample to the laboratory of Dr. Guy Rouleau at the Montreal General Hospital, 1650 Cedar Ave., Montreal, Quebec, H3G 1A4 where it will be screened for mutations of the NF2 gene.

[Editor's Note: Dr. Rouleau has recently become a member of the ANAC Medical Advisory Board and we look forward to his assistance in the education and support for our members.]

Yesterday is a cancelled check; tomorrow is a promissory note; today is the only cash you have - spend it wisely.

Kay Lyons

★★★★

"A bad habit never disappears miraculously; it's an undo-it-yourself project."

Abigail Van Buren, Universal Press Syndicate



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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

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

Enclosed ☐ \$28 - 1995 membership

☐ \$200 life membership

☐ \_\_\_\_\_ donation

Comments: \_\_\_\_\_