Connection

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

Vol. 9 Issue 1 April 15, 1996

Why Me? Dealing With Anger



by Maureen Mann

(Reprinted with permission from SHHH, Self-Help for Hard of Hearing People Inc., #1200-7910 Woodmont Ave, Bethesda, Maryland, USA 20814. Copyright 1995)

Ms. Mann has been a mental health therapist for the past nine years at the Boys Town National Research Hospital. She is currently an Aural Rehabilitation Specialist III at Boys Town and works with parents and toddlers who are deaf and hard of hearing. She received her master's degree in agency counselling with specialization in deafness, in 1983, from the University of Nebraska in Omaha.

A sense of anger, because of our hearing loss, is an emotion experienced by many of us.

Over time, if not dealt with, either through therapy or appropriate coping skills, anger can become entwined with hearing loss. To date, very little research has been done on his subject.

In this article, I want to address the topic from my own personal experience with hearing loss, and

from the personal experiences of many others who are hard of hearing. In the process, I want to share how we dealt with, or are still dealing with, our anger.

SHHH's focus is on people - specifically, people helping people. Consider the personal narratives regularly appearing in the SHHH Journal. Here we have a unique opportunity to learn and to tell others about our ongoing struggle to cope with hearing loss and the sense of anger that so frequently accompanies it.

A sense of anger, because of our hearing loss, is an emotion experienced by many of us.

Consider, too, SHHH's steady focus on constantly expanding resources, research and technology, and the ongoing review of the wide range of professional publications and assistance available to us. All these, together with the annual conventions and workshops, provide us with extraordinary learning experiences and coping strategies. After all, we have to learn how to deal with our anger and our hearing loss, before we can expect others to understand how they can help us.

In meetings with SHHH affiliates at the local level, we have the opportunity to come to the reassuring realization that we are not alone and that we and our fellow SHHH members experience in common a wide range of feelings associated with our hearing loss. SHHH affiliates provide a regularly scheduled time and place for members to share and compare and exchange experiences across the entire spectrum of hearing

REMOVE

loss. As our participation grows, we can find the support and understanding, and the resources we need, to help us cope with feelings of frustration and anger resulting from our difficulty in communicating.

Reactions to Hearing Loss

And yet, with all these resources, there are many among us who may still be experiencing anger. The question, "Why me?", is constantly in their thoughts. "Why did it happen to me? I was a hearing person; now I'm not." To one person, a hearing loss may be a major crisis, precipitating huge adjustments, career changes, new ways of communication, and financial and emotional hardships. Others may experience an identity crisis, typified by the unspoken question, "Who am I? What am I now that I have lost part of my vital sense of hearing?"

Whether a person was born with a hearing loss or acquired it during childhood, the teenage years can be extremely stressful, and the anger felt by rejection or teasing can be deeply rooted, leaving an emotional scar. Hearing loss in later life, too, can have a deep impact. For young and old both, the effect on self-esteem

continued on page 2



Acoustic Neuroma Association of Canada

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

Acoustic Neuroma Association of Canada P.O. Box 369, Edmonton, Alberta T5J 2J6 (403) 428-3384 1-800-561-ANAC (2622)

Email: anac@compusmart.ab.ca

Why Me?...

continued from page 1

can be devastating unless the person gets strong emotional support and learns viable coping strategies.

The initial reaction to having a hearing loss can run the gamut of emotions: shock, denial, depression, sadness, shame, and fear. I was born with a bilateral, moderate-to severe hearing loss which became apparent when I was about four. By age nine, I was introduced to a body aid. Suddenly I was different. I thought, "I'm not like the other kids. I can't hear well."

My perception of myself changed. It was not a good feeling; it was depressing, scary, in fact. My parents were supportive, but peer pressure in junior high and high school and the reactions of those around me made me feel there was a stigma attached to hearing loss. My self image, always shaky, now began wavering like a candle - flicker, dim; flicker, dim.

Today, all these years later, I want you to know that my candle is burning brightly. The main reason is that I was able to acknowledge my anger, recognize its negative impact on me, and work consciously to overcome it. I faced, and still face,

barriers, but I've chosen to perceive my hearing loss as a challenge. There were times when I felt like giving up. But, somewhere, I found the strength to hang on.

It has not been a smooth road. Looking back, I remember the anger more than anything else. I remember being angry with myself and with my brothers and sisters. I was angry and frightened, too, because my older brother - who had become profoundly deaf at age eight - was cruelly teased by other children. Now, it was happening to me.

Forgetting is not always easy. Forgiving isn't either. Where and how could I find the resources to help me move on?

I tried to hide my hearing loss and, in the process, became even more vulnerable. Hiding, denying, faking and constant guesswork were a big headache. Honestly, sometimes, I just plain got tired of bluffing. Being miserable gave me too much stress and compounded my anger and sense of helplessness. Years later, after taking courses on the psychology of deafness, I learned much more about myself, my anger and the so-called 'invisible' condition.

I had to learn to forgive. That

meant forgiving myself as well as others who either through lack of knowledge or lack of sensitivity, had hurt me while I was a vulnerable child. To heal, we must first deal with why we are angry at ourselves and others, before we can overcome anger. We have a choice. We can stay angry; feel ashamed; pity ourselves; be in denial, totally isolated and withdrawn from everyone.

Or we can make good use of what we have and use it constructively, not to our own detriment.

Accordingly, I don't ask, "Why me?" I just say, "Okay, what do I need to do to make my life easier and less stressful?"

The first step was the hardest, I had to acknowledge and I had to reach out. It is scary to lose what you had...to lose your hearing. I had to learn to say to myself, "It's okay to express these feelings and to say I'm scared." With that, I came to the realization that I am not alone. Help is there, for you, for me, but we need to seek it out.

Sharing is a second step. If I do not share with people that I am hard of hearing and that communication is difficult, the other person does not know what the problem is, much less

continued on page 3

President's Corner



by Shirley Entis

Several articles in this issue deal with life changes resulting from the AN experience. Emotions such as anger, frustration and loss caused from these changes are often unspoken and may not be recognized or dealt with for some time.

The article, Why Me? Dealing With Anger, shows that these emotions are experienced in all areas and stages of life, not only with AN. As well, ANAC members Brian Nichols and Doug Flood have courageously put their thoughts into articles so others understand, and in some cases relate to, what they and their families have gone through and how they are building their life after AN. We thank them for their time and commitment.

Associations also go through stages and changes and we have recently seen this at ANAC. As in personal life, they can be perceived as positive or negative depending on the understanding of them. Some of the previous life must be left behind and seen as history and recovery in order to make way for present needs and growth.

Through the work of its volunteers and members ANAC continues to change and grow. Their work and support continues to develop and expand local networks which, in turn, expands and develops the national base. In February, that expansion was acknowledged by a new national employee position of Executive Director. It has been capably filled by Ms. Lesly Round who is eagerly learning about the

world of acoustic neuroma. This important step takes ANAC into another phase of maturity.

EAPAN is also part of moving forward. It has been embraced with enthusiasm by the Montreal Chapter and new printed materials and workshops for the promotion of ANAC are being developed as we speak.

We, the members of ANAC, are a voice for AN people. The Connection is the voice of ANAC to open communication and healing. We want to be there whenever we are needed, and the change and growth of the Association keeps that mandate up-to-date. Personal emotions can be understood, developed and/or controlled by looking beyond oneself and helping others with their recovery and changes. ANAC s volunteers are proving that to be true.

I am asking you to communicate to our member-authors in this issue either by phone, letter or E-mail. As well, please call 1-800-561-ANAC and introduce yourself to Lesly. By working together we will continue helping each other.

See you in Vancouver!

Why Me?...

continued from page 2

how to help me. But by being up front, both of us know where we stand, and communication becomes possible. I don't always tell people I'm hard of hearing. It just depends on the situation. Sometimes it is difficult, but that's okay. We are human. But, believe me, faking it isn't always the solution. It's more stressful in the long run. Whether or not you tell someone that you have a hearing loss, chances are that the other person can usually figure it out. Most people won't bring it up, or tell you first, so it's up to us, you and me, to take the initiative.

Third, I have found that it is much more difficult to cope if you are still in denial. If you have a hearing loss, it is a part of you, but it is not who you are. The more open and up front you are, the more assertive you become. You start to feel good about yourself; your confidence grows. When people see that you respect and are honest with yourself, they will respect you, too. This building of mutual respect, then, is a valuable step forward.

Still angry? Stop and think about it. What good does it do to get angry and stay angry? You are only setting yourself up for more stress. This is destructive behaviour. It not only affects you, but also your friends, your family, your business associates. Turn it around.

Look at all the services and options that are available today. Start by searching for the finest hearing aid for your particular hearing loss. Then, go beyond the hearing aid itself. Consider assistive devices. Consider a cochlear implant if that's an option for you. As a fourth step, then, remain personally, actively involved in the search for a viable communication link with the hearing world. If you haven't done so

yet, get help from a professional your audiologist, ENT specialist, an educator or specialist in coping strategies - and, in the process, don't overlook the practical and proven exchange of ideas and information between you and your fellow SHHH members.

When you are doing this, you are growing internally. You may experience going in and out of the denial stage. You will feel confident saying "I am hard of hearing" to someone and then, later, you can't bring yourself to say it. One step forward...one step backward... forward...backward...it's a slow process. However, you know you are trying and heading in the right direction. Don't give up. To reach a desired goal requires some challenge, but the challenge can prove worthwhile. The end result is positive and rewarding, and so much more enjoyable than wallowing in self pity and blaming everyone else for our

normal, healthy, bot transitory emotion. I can (and do) get angry because I cannot find my darn hearing aids in the morning, even though I had trained myself hundreds of times to put them in a particular spot. I can get angry because a person with good hearing thinks I misunderstood something, when I didn't, but who has more credibility? I can get angry when someone who is hard of hearing makes a mistake or misunderstands something that was said, and, as a result, is assumed to be incompetent, or dense, or is excluded from further activities, conversation, responsibilities and opportunities. I

There's still a place for anger as a

myself is, "Keep on educating!" This means keep on educating yourself as well as others.

The important thing is to know who you are and to believe in yourself. If you feel you are being discriminated against or treated unfairly, stand your ground. If someone is not aware of the new climate that the Americans with Disabilities Act has brought to today's America, "educate" is the operative word, not "litigate."

To heighten awareness, start with self awareness. We need to heighten self awareness. We want to get along, not alienate.

To recap: It is okay to be angry at times, but it is not okay to hold on to that anger until it destroys your self-image, controls your life, affects your relationships with your loved ones, and damages or inhibits your career.

Life is too precious to waste; don't dissipate it on a destructive emotion. Use life, live life, positively.

Books to Look Into

Asserting Yourself: A Practical Guide for Positive Change by Sharon Bower and Gordon H. Bower. Addison-Wesley Publishing Company, Inc., 1991

Chicken Soup for the Soul by Jack Canfield and Mark Victor Hansen. Health Communications, Inc., 1993

Feel the Fear and Do it Anyway by Susan Jeffers, Ph.D. Ballentine Books, 1987

The Dance of Anger by Harriet G. Lerner, Ph.D. Harper and Row Publishers, 1985

Bringing Out the Best in People by Alan Loy McGinnis, Augsburg Publishing House, 1985

The Power of Positive Thinking by Norman Vincent Peale. Ballentine Books, 15th printing, 1992.

Welcome New Executive Director to ANAC



Acoustic Neuroma Association of Canada is pleased to announce the appointment of Lesly A. Round to the position of Executive Director.

can get angry when someone talks to

me as though I am a second-class

citizen, but what I keep saying to

Ms. Round has a strong business and administrative background with not-for-profit associations including the Alberta Chamber of Commerce, Canadian Hosteling Association, Home and School Association and the Alberta Restaurant and Food Services Association. She has worked extensively with business, industry, and educational institutions at provincial

and national levels.

A number of organizations such as the Canadian Society for Association Executives count Ms. Round as an active volunteer. In addition to raising six children, Ms. Round also supports her husband, Dr. Bill Forbes, in his role as President of Scouts Canada.

ANAC is on the brink of an exciting and challenging new chapter in our development and we are looking forward to having Ms. Round as a team member.

NF2 News - Coping With Deafness In A Hearing Family

by Brian Nichols

Since June 4th , 1991 my life has definitely been different. The isolation caused by the total and absolute deafness from my second AN surgery was very difficult for me to overcome. Although physical isolation seems to be the best coping strategy in the initial stages, it can lead to depression and low self-esteem in the long term.

I'm not sure that I would have adjusted to deafness as well as I have if it weren't for my wife Preeti, my parents and my best friend Gil. Deafness of course is a vicarious handicap in that we make other people write to us and play charades. Although the deaf person is trying as hard as he/she can to understand, it takes almost limitless patience to repeat/rephrase and then finger spell and/or write if all else fails. In our case deafness caused from AN surgery always is even more difficult because of the deafness being absolute, dry eyes, loss of visual acuity and tiredness particularly during the first two years.

Of course, it is only fair to say that many of my 'old friends' and most relatives don't have the time or patience to 'talk' to me. This of course really hurts as I have always loved having conversations about anything or even nothing. At 'family gatherings', I find that I am invisible as they almost never make eye contact or even signal

their comings and goings.

My old coping strategies included reading and rereading the paper, watching TV with zero percent comprehension or taking a nap. My new more militant stance includes AVOIDANCE of unpleasant social situations. Let's face it, a few minutes in an unfavorable social environment does more than anything else to undo months of improvement in self-esteem and happiness. So we try very hard to stay in contact with our friends and family that want to 'talk' to me or at least try to involve me as much as

With the help of the Bell Relay Service people could 'talk' to me for as long as they wanted to and they could avoid the messy charades and scribbled notes, but this has rarely happened either. Most family calls are routed to Preeti and then they leave it up to her to tell me what is going on. I have two FAX machines that they could also use to communicate, but

they still prefer to talk to Preeti.

We are extremely thankful for having two great kids. Daniel is now 5 1/2 and Erin is 1 1/2 yrs. There are numerous problems that I have to overcome when I am with them alone. Firstly, I have to stay in visual contact with them throughout the day as I would never know that they were crying or calling for help even if I was in the same room. This constant alertness extends to the playground, at the dock or even in the grocery store. A visual crib monitor in Erin's room and the receiver by the TV allows me a little more freedom while she is having a nap, but still I have to constantly be checking the monitor for crying or coughing.

Daniel can now be trusted to play in his room without my constant observation. However, it is very important for both of us that we know where each other is, at all times. Setting one hour play periods at his friend's house followed by a brief check-in and update keeps everything running

smoothly.

Secondly, I have to always anticipate what is needed as I can not wait for them or expect them to be able to communicate with me at this stage. Just keeping up with a 5 year old in a totally normal situation can be difficult, but being able to anticipate adds a new dimension. For example, if I forget to get the ketchup or honey for his chicken nuggets, I have a very unhappy camper. Once they start to cry it is almost impossible to speech read or play 50 questions. Luckily for me and the rest of the hearing world Daniel is very consistent and knowing exactly what he wants and in what order lessens the tension greatly.

Daniel and I have definitely had our rough spots. But fortunately now he understands that I am deaf and knows enough signs for the things that he needs. Cookies, Coke, Play, More, Apple Juice, Movies, Play with Train, Boat Ride, Help, etc. etc. Now that he is starting to write also helps as he augments the signs with written words on the magic easel. When Preeti gets a chance she tells me some of the things that Daniel is telling her. I would still like to know more about his life, but I try to be as involved as I can.

He makes a point now of telling me when a cartoon is closed captioned so that we can watch it together. I know that our family situation will never be

'normal' as communication will always be difficult, but not impossible. As Daniel learns to write more words I can hope to have longer 'conversations' with him.

As soon as possible I am hoping to get a voice recognition system for the computer to allow everyone to 'talk' to me more easily. Although Preeti is my main interpreter she still has to abridge every conversation. Even with her help I am still only getting the bare minimum and missing most of Daniel's questions. So a voice recognition system would allow me to chit-chat with Daniel on my own.

Thirdly there is no 'Cause' and 'Effect' when looking after kids. If I miss seeing the 'Cause' of why they are upset then just seeing them cry has very little 'Effect' on me. Generally. and there is probably some marvelous psychology theory to explain this, whether a child has scratched his/her finger or is one second away from cardiac arrest from electrocution all crying behavior looks the same. So often they get an inappropriate response from me. To avoid this problem as much as possible everything in the environment has to be child proof and I have to double up on the visual patrol.

Lastly, there are no accolades for being a deaf person in a hearing family. So far I haven't missed out on one single phase of my life because of NF2 and plan to continue to live my life to the fullest. There are definitely problems but they can be overcome to a great extent. I don't want people to think of me in terms of..."There goes that Deaf Guy," but rather..."There goes that Engineer,

Husband and Father."

ANAC is Now On-Line

Email:

anac@compusmart.ab.ca

Homepage:

http://www.compusmart.ab.ca/anac (under construction at the moment)

News and Views from the Chapters

April 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

- Evalyn Hrybko, BC Provincial Coordinator
 Box 38, Sayward BC VOP 1RO
 604-282-3269
- Heather Horgan, Vancouver Chapter Contact 3011 Reece Avenue Coquitlam BC V3C 2L1 604-464-2625
- Wenda Deane, Vancouver Chapter President 2788 West 1st Avenue Vancouver BC V6K 1H3 604-736-1215
- Harry Kraeker, Victoria Chapter Contact #306-1655 Chambers Street Victoria BC V8T 3J7 604-384-7530

Report from Heather:

Our Annual General Meeting was held February 21/96 and attended by 16 people. Election of officers was held followed by an informative talk by guest speaker, Grace Lee.

Grace is an audiologist at the Western Institute for the Deaf and Hard of Hearing, and her particular interest is in hearing aid technology and other assistive listening devices.

She brought a number of these devices with her and demonstrated their use and how these may be beneficial to persons with unilateral hearing loss.

Grace was somewhat surprised that no one present had ever tried a CROS hearing aid. She pointed out that it may be more beneficial to try

the CROS fairly soon after hearing loss because as more time goes by the brain tends to make its own adjustments or compensates for the unilateral hearing loss in its own way. Therefore, if you were to introduce the hearing aid much later, it would in fact be another adjustment to make. There still are problems with speech discrimination while wearing a CROS but it assists one's hearing on the 'bad' side by transferring that sound to the 'good' side.

Our next local meeting will take place in the Fall as we will be busy with the Symposium in May/June. Hope to see many of you there!

We would also like to wish physio-therapist and ANAC Director, Susan Rankin and her family all the best on their recent move to Victoria. Her clinics will be continued in Vancouver once a month on a Friday and Saturday as needed. To contact Susan, please write or call:

Rankin Physiotherapy 182 Beach Drive Oak Bay, BC V8S 2L7 Tel(604)595-0440

Alberta

Report from Verna:

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

FOOD! FUN! FRIENDSHIP! GIFTS!

Our Edmonton Chapter had its second annual Christmas party December 15th at my home.

Fifteen people came out for a very enjoyable evening. Thanks to Joey Pickering for bringing the 'mind-bender' game of world capitals. Everyone chipped in bringing goodies and we all had a great time.

Linda Gray and I put everyone to work punching and peeling snowflakes for the ANAC Holiday cards.

Loretta Miller, Hilda Rankin and Linda were guilty of stealing but everyone went home happy.

Manitoba

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

Report by Leslie

In November Dr. Leelamma Nielsen came to our group meeting to talk to us about the practice of holistic medicine which tries to look at the whole person, not just specific symptoms. It was an informative evening and while no one discussed specific cases, we all came away with a beginner's knowledge of the goals/objectives of doctors who practice this form of medicine,

In January Dr. Derek Fewer, a prominent Winnipeg neurosurgeon, joined our group discussion and participated in a general question/answer session. We try to invite one of the neurosurgeons to visit our group at least once a year. Everyone finds these meetings to be very informative, and we feel it helps instill in the specialists the fact that we are real people with definite problems that the surgery has not fixed and often has produced.

In February, we were visited by a local massage therapist.

Please note: The massage therapist is presently working on a thesis and hopes to use survivors of benign brain tumors as her study group. She requires volunteers who would come to her office on a regular basis for several months for therapy. She is hoping to not only provide with information for her thesis, but give benefit to those who are chosen to participate. Anyone interested in learning more about this project and participation

in it, please contact me at the above phone number.

Ontario

- Ann Sloan, Ottawa Contact 2052 Gatineau View Crescent Gloucester ON K1J 7X1 613-746-7992
- Barry Singerman, Toronto Contact
 Wimpole Drive
 Willowdale ON M2L 2L3
 416-443-8909
- Doug & Eleanor Flood, London Contact
 11 Outer Drive
 Lambeth ON NOL 1SO
 519-652-3417 (TDD & Voice)
- Trenny Canning, Kitchener/Waterloo Contact 52 York Street Kitchener, ON N2G 1T3 519-579-4855
- Frank Fusca, National NF2 Contact
 58 Tidefall Drive
 Scarborough ON M1W 1J2
 416-495-8979 TDD

Toronto Report from Barry:

Arrangements are being finalized for a Chapter meeting the end of May or early June. Please watch for details in a separate mailing.

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 from Trenny:

Inaugural Meeting of K-W Chapter:

- Thursday, April 11, 1996
- University of Waterloo
 Hagey Hall of the Humanities, Rm 378
- Speaker: Dr. Lisa Prokopich
 Solutions for Dry Eye... After The Tears

It is exciting to have a chapter of ANAC in our area and I am eager to meet with local people. Let's build it together.

Please call me and introduce yourself, or be sure to stop and chat at the meeting.

If you know of someone who would like to receive notices of future meetings, please let me know.

Quebec

- Marie Legault, National Director/Quebec City Contact
 95 Place Vanier
 Courcelette, PQ GOA 1RO
 418-844-2144
- Marie Catherine Lescouflair, 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 from Marie Catherine:

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

"Travel News for Montreal"
Re: ANAC Symposium, Vancouver BC
May 31-June 2, 1996

It will be my pleasure to make your travel arrangements for airlines, hotels, cars, and insurance for this special event. Call early for best prices and accommodations. Arrangements can be made with all major airlines and hotels.

Stoopler Travel Inc. (514)843-3800
Fax (514)843-3143
OI my home no. (514)345-9364
(No collect calls please)

Hope to hear from you. Hilda Raby, Travel Consultant

EAPAN Report by Janey Veneziano

The EAPAN Planning Committee is eagerly making arrangements for the EAPAN Workshop to be held May 25th, 1996. Watch for the complete agenda in your mail the beginning of May.

Topics for the day include Being A Voice For Acoustic Neuroma; Acoustic Neuroma - A Medical Perspective; Coping Strategies; New Avenues Of Funding

ANAC displays are planned for three events coming up: Brain Tumor Information Day, April 27th at the Queen Elizabeth Hotel, Montreal....Canadian Family Physicians Conference, May 17 & 18 in Vancouver....Facial Therapists Study Group, May 29 & 30 in Vancouver.

Members of the Planning Committee are diligently working to have new information materials available to hand out at these events

Nova Scotia

Anna Parkinson
 52 Auburn Avenue
 Halifax B3R 1K5
 902-477-2396 TDD
 Nova Scotia Chapter Contact for Acc

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

Report from Ed Morrisey:

Did you make any new, good resolutions for 1996??? New courses in lip-reading or new exercises? Or your good outlook on life?

Lindsey volunteered to be our representative for the board of National Access Awareness Week. He will attend with David Spencer who is there on behalf of the Deaf Association.

A big 'Thank You' to Jack Fry for his assistance regarding Revenue Canada forms.

Best wishes in the form of a card and small bunch of flowers arranged in an AN mug were sent from the Group to two members after their recent surgeries. Another member had successful Gamma Knife treatment in Rhode Island.

The Carol Sing at the Dec. meeting was conducted by James Bond and everyone sang to their heart's content - even though there was no one to play the piano!! It is expected the Mormon Choir will beat a path to the door!!! (eat your heart out, choir director)!

Here's a riddle from Peggy:

The man who made it, doesn't want it.

The man who bought it, won't use it.

The man who uses it, won't see it.

What is it???

Answer: a coffin.

Please continue saving cash register slips from IGA and Soby's...and don't forget your dues.

National Office, Edmonton

Report from Linda Gray, Program Manager:

1996 has started out very busy and exciting. Verna Thoman, Michelle Rurka and Lesly Round (in order of 'date hired') have joined the ANAC staff. Their expertise is a tremendous help to the National Office.

Lesly, Verna and I will be attending, and helping with, the ANAC Symposiums in Vancouver. We are looking forward to seeing many people we have corresponded and talked with, as well as meeting new ones. The agenda's looks great!

Information on New Products on the Market

EASY LISTENER by PHONIC EAR

A personal FM system with a receiver, transmitter and charger. It is small and compact with sound travelling for about 150 feet. Available from AMERIPHONE 7231 Graden Grove Blvd. Ste E, Garden Grove CA USA 92641

WALKER CLARITY

A unique telephone specially designed for those who have moderate or severe hearing loss, especially high frequency. With a single touch of the Clarity Control switch the high frequency sounds are increased more than the low. It is the only phone with a patented, built-in equalizer that automatically tunes, tones and balances sounds to give you perfect clarity.

Contact your local telephone companies and/or agencies for more information.

THERA TEARS

A new eyedrop for dry eyes. Containes no preservatives and is "fortified with a unique patented electrolyte balance that works for the eye much like the drinks athletes use to replenish natural body fluids during and after a workout. A balanced blend of fluid and electrolytes are provided to the eye surface, creating the environment needed to promote natural healing and provide dry-eye relief". For information: Advanced Vision Research, #330-7 Alfred St. Woburn, MA 08101 (Tel)1-800-5-RX-TEAR; (Fax)617-935-5075

GUIBOR BANDAGE

A clear plastic moisture chamber for dry eye problems. Now available through ANAC. \$30/pkg of 10. See details in this issue of the Connection.



21-27 April 1996

"We can do no great things only small things with great love." Mother Teresa

Mailbag

Dear ANAC,

My motto is: No trial; no triumph! I had my AN surgery on June 30, 1988. As a travel agent I am part of a company group insurance. In the past I submitted a letter from my neuro-ophthalmologist to the insurance company requesting payment for my Lacrilube because it is a necessity not just a dry eye.

Since then my employer has changed to another insurance company and once again I wrote with my request. This time I hit the jackpot, and am very lucky because they have agreed to pay the total cost of my Lacrilube. It's like I won the Lotto!

Unfortunately, they rejected my request.

For anyone else who can benefit from a similar submission, I am enclosing a sample of the letter my neuro-ophthal-mologist wrote for me, and which I submitted.

To whom it may concern:

This is to certify that Hilda Raby needs to use Lacrilube ointment regularly to her right eye. She had an acoustic neuroma with facial paralysis and corneal anaesthesia on the right.

This is not just simply a patient who needs to use the ointment because of dry eyes. Rather she needs it for the rest of her life to preserve the condition of the right cornea.

Yours sincerely,

Neuro-ophthalmologist

If anyone has questions regarding this please have them write or call me.

Hilda Raby #605-4530 Cote des Neiges Rd Montreal PQ H3V 1G1 514-345-9364

Dear ANAC,

In Aug/94 I underwent 19 hours of surgery to remove a 4cm AN at the University Hospital, London ON by Drs. Lownie and Parnes.

I guess my surgery was a success, although sometimes it's hard to be appreciative given I had relatively no symptoms prior to surgery



other than some dizziness, and now suffer from unilateral hearing loss, partial facial paralysis, dry eye and up to recently, constant, debilitating headaches.

I was 30 years old with a husband, two children (1 1/2 and 3yrs.) and a full-time career. I had tried numerous methods to rid myself of and/or manage the headaches including medication (Tylenol #3), cranialsacral therapy, physiotherapy, massage therapy, chiropractic therapy and psychological counselling.

In my quest to alleviate these headaches my research was helped greatly by Mailbag letters and articles from ANAC and ANA(US). I found that although rare, instances of severe, constant headache were more common with the sub occipital/retrosigmoid surgical approach, especially if the cranectomy bone flap was not replaced. Research showed that soft tissue could adhere to the dura (brain lining) through the hole .1 spoke with several people who had the hole filled post-operatively (cranioplasty) and was rewarded with the knowledge that it worked for some, but not for others!

Notwithstanding, I was willing to try it. My neurosurgeon agreed it could work and performed the surgery. It took approx. 11/2 hours and I woke up feeling lousy (apparently some patients wake up headache free!). After the surgery my neurosurgeon said there was some adherence of tissue to the dura, he separated it and filled the hole with an acrylic plate.

Now 5 months post surgery I still have headaches but they are in no way comparable to the headaches I had been experiencing and, with luck, will disappear completely. They seem to be caused more from incisional pain, especially in my neck,

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.

rather than internal pain. The headache I experience now, is more of a normal headache and is alleviated by relaxing. Two extra-strength Tylenol in the morning allow me to be pain- free an entire day! I now feel I have control over my life and am able to participate in physical activities with my children.

I also found a wonderful optometrist who has several solutions to dry eye, including semi-permanent silicon plugs to provide maximum blockage of tear drainage. I've been experimenting with temporary collagen plugs. For the first time since my first surgery my eye is not irritated and I don t have to use any eye drops!

Trenny Canning 52 York Street Kitchener ON N2G 1T3 519-579-4855

Editor Note: Trenny has recently volunteered to be ANAC contact person for Kitchener-Waterloo area. The first chapter meeting will be held on April 11/95 so please call her for the details.

Dear ANAC.

I am 62 years old and had a 2cm AN removed Oct/95. I came through the surgery with few side effects: loss of hearing in left ear, tinnitus which is quite loud at times, and some balance problems. My thanks to my great surgeon, Dr.Tator and his assistant, Maria who were very helpful and patient to someone as nervous and scared as I was. The operation turned out better than I expected and 2´ months later I was caring for my 15 month old granddaughter again.

I enjoy receiving the Connection. It is very informative, and when I read of others with many side effects after surgery I thank God I was one of the lucky ones.

Shirley Pierce 1995 Royal Road, Unit 106 Pickering ON LTV 6V9



The Guibor Bandage is "a selfadhesive dressing with clear dome window that applies in seconds." It supplies an airtight moist chamber for: dry eye syndrome; VII nerve palsy; protects eyes during anaesthesia; postoperative dressing. For those who wear eyeglasses the flat bandage is specially designed with a flat, clear window.

Guibor Bandage Supply Sold in Two Months

The Guibor Bandage cannot be purchased in Canada anywhere on the retail market. In order to better serve ANAC members as well as other "dry eye people," ANAC CANADA will now stock both bubble and flat Guibor Bandages for personal and institutional use.

ANAC's first supply of 500 bubble Bandages was sold in less than two months and reorders came in VERY quickly. Response to questionnaires sent in with initial orders were positive and enthusiastic with considerable interest expressed in trying the flat ones.

To place an order call:

(403) 428-3384 1-800-561-ANAC

E-mail: anac@compusmart.ab.ca

Cost:

Members - \$30/pkg of 10 Non-members - \$45/pkg of 10 Price includes postage & handling Payment to be received with order.

Doug's Story: A Spouse's Point of View

Doug Flood has personal understanding of the support and reassurance needed when dealing with the acoustic neuroma experience. His story is the first to be published from a family member's point of view and we thank him for it. Eleanor and he have recently volunteered as contact people for the London, Ontario area, and we look forward to working with them.

My wife, Eleanor, started developing problems with her balance in the early 1960's.

While at the C.N.E. in Toronto we went into a hearing aid display and had our hearing tested. Her left ear was very bad. Her right ear was normal. We had a heated debate with the salesman over the use of a hearing aid for her, and as was pointed out to him hearing doesn't diminish dramatically on one side and not the other. If it was a natural thing, both would be low.

Eleanor kept putting off going to have her ear looked at. Her balance got worse and in 1969 she finally went to a specialist. He did the water test and found the brain tumor on her left side. We were told it was an acoustic neuroma and an appointment was made with a brain surgeon. We are fortunate to have in our city of London one Dr. Charles Drake, a world renowned brain surgeon.

Eleanor's operation was in January 1970. She was 38 years old at the time. He explained to us the growth of a tumor, how it grows in a capsule, and that the whole thing should come out.

I was prepared that there may be a little paralysis as the 7 & 8 nerve could be affected. We were not prepared for what the results produced: total paralysis on her left facial side; the eye wouldn't shut; the face was totally flat; her mouth was deformed. After 18 days in the hospital she came home.

I must confess I was devastated. She wouldn't go out as she thought of herself as a freak. Finally, after not leaving the house for 6 months, I forced her to go out. She returned to her job as a payroll clerk with the federal government.

She underwent several operations to try and correct her facial paralysis with some success. In 1982 we got a bi-CROS hearing aid because, as you can understand, with the hearing gone



Doug and Eleanor Flood

in her left ear it was difficult for her to hear. When we were out in public or in the car she was always on the wrong side.

There was also another reason. Her hearing in the right ear had started to go down in 1979 and 1980. She told me in early 1988 that there was something in it. A trip to the specialist confirmed another acoustic neuroma had developed. It was decided to try the GammaKnife instead of surgery in the traditional form.

We went to Pittsburgh, Pennsylvania to the Presbyterian University Hospital as they had, at that time, the only machine in North America. She underwent treatment that lasted 18 minutes, spent 3 1/2 days in the hospital and it cost over \$25,000. Thank God for OHIP as it was totally covered by it.

It was hoped this treatment would save her hearing but this was not to be.

In the winter months we enjoyed going to the Sunday Pops, and while at the last concert in the Spring when the people were clapping at Intermission Eleanor said to me she could see them clapping but couldn't hear them. She had gone totally deaf sitting there. We left.

I didn't mention she also has a third tumor in her brain. It is on the back part of it. She has an MRI scan every two years to check on the existing two tumors and they are not growing but just there. I understand she has a form of Neurofibromatosis where the tumors grow on the inside nerves. Her brother, who is about the 10th member of the family with tumors, also has two acoustic neuromas. I tell everyone it's a bad gene and in her case I know it is because her name is Eleanor Jean!

Now the good parts...

* We have closed caption TV, and for your information any TV produced after June 1994 must have it built in. * We have a TDD machine. We also bought one for our daughter in Florida and now Eleanor calls her direct without BRS.

* We go to the theatre in the winter and the summer also. They give us copies of the plays, she reads them a couple of times and then can follow it on the stage.

* We have a teaching hospital in London and the University of Western Ontario. They have been most helpful. The Audiology students and Speech people took us under their wing and slowed down my speaking and showed us simple little things to make her a better lip reader.

It is an eye opener though, because the number of friends we had don't come around like they used to. We can cope with them but they can't cope with us, I guess.

People don't realize how life can be changed by these things. At night if you want to talk you must turn on the lights. When you are driving and she wants to talk, you either park or try driving with the lights on in the car. Of course I must look directly at her so she can read me and that makes it dangerous. Also your billing and cooing is changed as she can not see it or hear it.

We do not sign nor do we write notes. I will change the words so she can read me. She misses not being able to drive but has kept her license up in case she ever has to.

We are very pleased to be ANAC's new contact in the London area and are looking forward to helping persons with this affliction to have a better life among understanding people.

All is not lost - there is a life out there and we enjoy it. We understand we must have our space. I spend a couple of hours a day in the basement making tapes. I have over 23,000 records and am taping them. She is a very avid Bible reader etc. and recently had a cataract removed from her right eye.

We have had our times, but we have been together 45 years and plan to keep it that way.

Doug & Eleanor Flood 11 Outer Drive London ON, NOL 1SO 519-652-4317 (TDD & voice)

Living With a Brain Tumor

Learning to live with a chronic or potentially terminal disease is not easily achieved, for the patient or his/her family. The range of problems encountered after diagnosis of Brain Tumor can be enormous. Initially, there is fear, anger, uncertainty and loneliness. There is a need to learn how to deal with this overwhelming news, and how to live under its cloud.

When a Brain Tumor is diagnosed and treated, it seems that we lose control over many areas of our lives. It often helps to focus on what we can control and do to help ourselves and our families through these difficult days. Following are some guidelines which may help.

Seven Suggestions for Living with a Brain Tumor KEEP OPEN COMMUNICATION

Honestly sharing fears, hopes, and frustrations among family members can relieve loneliness, anxiety and enforce the support family members need from each other. Openly discussing diagnosis and treatment with your doctor, including freely asking questions, helps lessen the helplessness and frustration you may feel.

LEARN AND RESPECT YOUR OWN LIMITS

If you are tired from radiation treatments, tense about tests, not eating well, etc., perhaps it's time to be kind to yourself. Learn and assert your needs, so that you can face your treatment in the best possible physical and emotional state. It's okay to be selfish.

Dry Eye Bubble -Guibor Bandage

A CANADIAN BREAKTHROUGH!

ANAC Member price: \$30/pkg of 10

Non-member price: \$45/pkg of 10

Price includes postage and handling. See article for details.

LEARN TO RELAX

A stress management class, yoga course, or regular exercise may help you reduce the tension you may be living with. Learning to use visual imagery may also help.

DEVELOP A FAITH OR PHILOSOPHY

Many people with brain tumors have been helped by attempting to find some meaning or purpose in their personal situations. Seeking religious or philosophic answers to the questions of serious illness, suffering, life and death can make what seems unbearable easier to accept.

ACCEPT THE ASSISTANCE OF OTHERS

Now is the time in your life to let others help you, in whatever way you feel comfortable.

FOCUS ON THE PRESENT

Learning to appreciate each day is not something most of us have been taught in this future-oriented society. It is very easy to let the present vanish as worries about the future crowd in. It is also easy to make comparisons as we think back on past, more carefree days. Although we can never banish such thoughts completely from our minds, we can learn with discipline and new insights, to appreciate the present, living to the fullest each minute, hour and day.

READ ABOUT OTHERS

Finally, learning about others who have faced brain tumors or other life-threatening conditions can provide help. Through the examples of others we may gain insight on how to cope.

Courtesy of the American Brain Tumor Association, 2720 River Road, Des Plaines, IL, USA 60018; (800)886-2282)



BOOK NOW!

ANAC Symposium

Vancouver Chapter presents

FROM PATIENT'S POINT VIEW

- Don't Wait!
- Last Chance!
- Register Now!

SEE YOU AT THE SYMPOSIUM

Vancouver BC May 31, June 1-2, 1996

Registration materials are included with this edition of the Connection.

For further information contact:
Wenda Deane

(604) 685-1014

Special Thanks to Our Contributors

December 1, 1995 to February 29, 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 for their most generous donations to ANAC! Canadian Imperial Banks of Commerce Pipe & Pipeline Supplies Ltd. Susan McCullough Shirley Falls

Life Members R. Gordon Dabbs Noline Vallee

General Donations Debbie Cole Kathy Bednarek Else & August Schech Elizabeth Ford Henri Duranleau Klara & Gregory Zazkis Nelda Tabler Judy Baribeau Vince Ramsay Clifton & Valerie Sandford June Truant John Retzlaff Merton Brown Stephen & Ilana Ruby Marina Marko Murray Belanger Stuart B. Doak Annie Sjogren Dr. Bernard Hoddinott Helen McGowan Kathryn King Luisa Catenaro Brian Somer Linda Gray Irma Arnold Louise Haggerty Isabel Shuster Myrna & Ken Douglas Dr. Jean Jacques Dufour Danielle Melanson Georgia Russell John & Donna Scherer Dr. Georg Noren Hazel Martin Reva MicFlikier Maureen Bragg Matilda Foster Isabel Shuster Robert H. King Robert Hawkins Isadore Coop Marguerite Poirer Marguerite Mah Annie Sjogren Denise Guibault

Jo Hinchliffe

Clarence Jaynes Anne Castaing Cicelia McMurtrie Joyce Sjerve Eila Taylor S. Rosemary Thompson John Campbell Allan & Shirley Craswell Shirley Kolanchey Susan Rankin Glenn Lockwood Shirley Ball Norman Zanolli Audiology Clinic of Northern Alberta Shirley Kirkwood M. Yoshioka Brett Thibert Cynthia Rosenberg Brenda Smith Richard Davine

Edward Morrisey Nancy McFarlane Karen Keily Susan Stuttard Judy Nickol Dr. Isaac Fried Moira Maurice Yolande St. Martin Joan Rhead Oscar Fulton Gregg Rogers Dr. Ron Moore Jane Hrynchuk June Truant Gladys Bartlett Gheorghina Szasz Andre Malo lim Gehon

Ken Johnson Dr. Nancy Van Laeken Marie St. Germain Eva Bayliss Leonard Wert Victor Boszar Gibson Medical Resource Centre Mary Berlin

Celine Guerin Towner

Samuel Kloda

Sharman Investment Corp. Ioseph Drazin Kevin Milne Ioyce Fauchon Dr. Morgan Brosnan Ioan Parks Bridget Barker Dr. M. E. Ashenhurst

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

Dr. George Novotny Peter Maslanka Patricia Fry Gino Hamparian Anna Savas Pam Fretz Wayne MacDonald The Audiology Centre Catherine Francis Eileen Hanafin Patricia Pilon Viola Schneider Smaro Merrigan Douglas Specht May Sterparn Elizabeth Cunningham Irma Arnoid Libby Pistreich Betty Young Kathleen Guchardi John Cant Ioe Taylor Carolyn Shaw Mary Stewart Manfred Soehnel Maria Zanolli Norman Sharpe Luisa Catenaro Stewart Kates Tino Dimanno

Tino Dimanno
The Moncton Hospital,
Speech & Hearing
George Ibrahim
Betty Wood
Ann Matte
Michelle Rurka
Susan & Joseph Portnoy
A. & S. Gonshor
Herb & Evelyn Steckler
Rosemary Higgs
Abraham Drazin
Lorraine Simpson

Lorraine Simpson Yehuda Leitner Ursula Gold Roger Racine Angie Van Groningen Alan Robins Anne Riby Valerie Wicks

John Soilows Laurie David Judy & Bruce Henderson David Sarkany Wanda Browne

General Memorials Dr. & Mrs. D. Rimoin, loss of grandfather Frank & Shirley Entis & family In Honor Of

Joey Pickering's 65th birthday Shirley Entis Irma Arnold, A Speedy Recovery Shirley Entis Kirby Kennedy Michelle Rurka Linda Sacht, Happy Holidays Penelope FitzGerald Linda Gray & Michelle Rurka, Merry Christmas

Verna Thoman
Arlene & Sam Trager's 40th
Anniversary
Evelyn & Alan Huberman
Luisa Catenaro's birthday
Mark & Diana Milner

Paul & Josephine Catenaro

Rosanne Rosen Memorial Fund

General Donation Lana Rosenwald

In Memory of Barbara Fishman Phyliss Rosenbaum Morton Grostern's mother Dr. Michael Rosengarten's mother

mother Hascal & Sandy Rosen Mr. I. Rabinovitch's father Shirley Entis

In Honor of
Hascal & Sandy Rosen,
Seymour & Selma Rosen
for your warm hospitality
Jerry & Lorry Cooper
Mr/Mrs Stanley Diamond,

Mr/Mrs Stanley Diamond, Happy 30th Anniversary Hascal & Sandy Rosen Mrs. Wm. H. Cohen, Happy 90th Birthday Hascal & Sandy Rosen

Hascal & Sandy Rosen

We wish to express our appreciation to Alberta Repro for their continued donation of reduced costs for printing the Connection

Health and Welfare

Santé et Bien-être social Canada

Please enroll me as a member of Enclosed \$28 - 1996 membership Acoustic Neuroma Association of Canada □ \$200 life membership donation Box 369, Edmonton, AB, TSJ 2J6 Name: __ Address:___ Province: Postal Code: Phone: (Bus) _____ (Res) ______ Age: _____ __ (optional) **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: _ Charitable Registration #0677682-11

Network of Contacts

Head Office: (403) 428-3384 1-800-561-ANAC (2622) Email: anac@compusmart.ab.ca

Executive Board

SHIRLEY ENTIS
President

JONATHAN KANTOR
Vice President

VIRGINIA GAROSSINO Past President

SUSAN RANKIN Secretary

JAN STUCKEY Treasurer

JACKIE DIELS Facial Neuromuscular Retraining MARIE LEGAULT Publicity IRMA ARNOLD Stereotactic Radiosurgery

TOM RIGLAR Director

Emeritus
GEORGE CAMPBELL
VELMA CAMPBELL

VELMA CAMPBELL RICHARD GAROSSINO LINDA GRAY

Medical Advisory Board

TATOR, CHARLES, M.D. (Chairman) Toronto Hospital

Toronto, ON ATTIA, Elhamy, M.D.

University of Dalhousie Halifax, NS BROAD, R.W., M.D.

University of Alberta Hospital Edmonton, AB

DUFOUR, Jean-Jacques, M.D. Hôpital Notre-Dame Montreal, PQ

HODDINOTT, Bernard, M.D. Private Practice Belleville, ON

HURWITZ, Jeffrey, M.D. Mount Sinai Hospital Toronto, ON KONDZIOLKA, Douglas, M.D. Presbyterian University Hospital Pittsburgh, PA

LONGRIDGE, Neil, M.D. Vancouver General Hospital Vancouver, BC

MOHR, Gérard, M.D. Jewish General Hospital Montreal, PQ

PARNES, Lorne, M.D. University Hospital London, ON

ROULEAU, Guy, M.D. Montreal General Hospital Montreal, PQ

Emeritus BALLIET, RICHARD, Ph.D. GULLANE, PATRICK, M.B. OLDRING, DERALD, M.D. NEDZELSKI, JULIAN, M.D.

National Contacts

Provincial Coordinator BRITISH COLUMBIA Evalyn Hrybko, Box 38 Sayward, BC, VOP 1R0 604-282-3269 NF2 CONTACT Frank Fusca 58 Tideialf Drive, Scarborough, ON, M1W 1J2 416 495-8979 (TDD)

STEREOTACTIC RADIOSURGERY Irma Arnold Box 42, Site 305,

Box 42, Site 305, Wasaga Beach, ON LOL 2PO 705-429-2484

Provincial Contacts

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

BRITISH COLUMBIA Heather Horgan 3011 Reece Avenue, Coquitlam, BC,

V3C 2L1 604-464-2625

ALBERTA

ALBERTA Verna Thoman

15216 - 63 Street, Edmonton, AB, T5A 4V7 403-456-5468

SASKATCHEWAN Bev Swavze

18 Richmond Place N., Saskatoon, SK, S7K 1AS 306-242-9040

MANITOBA Leslie Sutherland 36 Valleyview Dr., Winnipeg, Mil, R2Y 0R6 204-837-5280

ONTARIO
Barry Singerman
50 Wimpole Dr., Willowdale, ON,

MZL 2L3 416-443-8909

QUEBEC

Romas Staskevicius
6121 LaSalle Blvd., Verdun, PQ,

H4H 1P7 514-766-6072

QUEBEC (Francophone) Catherine Lescouflair 293 Place Samson, Chomedey Laval, PQ H7W 3T8 514-682-8680

NEW BRUNSWICK Barbara Theriault P.O. Box 22, Grande Anse, NB, E0B 1R0 506-732-2993

NOVA SCOTIA Anna Parkinson 27 Feldspar Cres., Kidston Estate, Halifax,NS 83R 2M2 902-477-2396 (TDD)

PRINCE EDWARD ISLAND Irene MacDougal R.R. #1, Richmond, PEI COB 1YO 902-854-2958

NEWFOUNDLAND Exie Malone 10 Hemmer Jane Drive, Mount Pearl, NF A1N 4V3 709-747-1202