

the Connection

Published Quarterly by the Acoustic Neuroma Association of Canada

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

Vol. 7 Issue 3 November 1, 1994

PLEASE - DO NOT REMOVE

University of Alberta Hospital Skull Base Surgery Team

Dr. Derald Oldring is Director, Division of Otolaryngology, Department of Surgery; Surgeon in Chief, Otolaryngology, University of Alberta, Edmonton; and a member of the Medical Advisory Board, Acoustic Neuroma Association of Canada. As one of the surgeons involved in the team approach when dealing with acoustic neuroma he has written the following article about the hospital's work.

Historically, acoustic neuromas (AN) and other basal skull tumors seen in Alberta have been treated primarily by neurosurgeons. Otolaryngology and other surgical disciplines have been involved to a lesser degree, mainly treating smaller tumors. Because a substantial number of patients had traditionally chosen to leave western Canada to receive treatment, problems with complications and aftercare resulted when they returned to their home communities. The University of Alberta Hospital (UAH) made a decision to help rectify that situation.

In the 1980's UAH decided to pursue a team concept to deal with skull base tumors. This followed the exposure of a small number of UAH surgeons to training opportunities and contact with doctors and patients in world centres where such treatment had been developed. More recently, two otolaryngologists on the UAH staff have undergone one-year post-graduate training fellowships in skull base surgery, adding substantially to the research expertise and educational level of our skilled team. Since 1989, our current team of



surgeons has performed over one hundred acoustic neuroma removals, in addition to a substantial number

of other types of tumors. UAH currently accepts approximately 35 AN patients per year mainly from Alberta, Saskatchewan, and northeastern British Columbia.

Our skull base team, in addition to the standard surgical members, includes audiologists, vestibular laboratory technicians and three neuro-radiologists who have various types of imaging available, most notably Magnetic Resonance Imaging (MRI) and Computerized Axial Tomography (CAT) scanning. Three anaesthetists, specializing in neuro-anaesthesia, serve the team on a rotational basis.

Our equipment, which is continuously updated, includes several monitors to evaluate the facial nerve during surgery as well as the patient's hearing, should hearing preservation be attempted. Equipment that follows facial nerve function and predicts recovery is also available. Recently the hospital invested \$150,000 in a new microscope system to aid the surgical team.

While most patients undergo surgical removal of their tumor, a

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Driving After Diagnosis of a Brain Tumor

Reprinted with permission from the Adult Version: Brain Tumor Patient Resource Handbook, Brain Tumor Foundation of Canada

The ability to operate a motor vehicle is a privilege, not a right. Many patients with a tumor are advised not to drive. To a patient with a brain tumor, it is often a denied right. The loss of the ability to drive can lower one's independence and self-esteem and become a source of great frustration.

The need to withdraw driving privileges from a brain tumor patient who has a seizure disorder is fairly straightforward. It is the law in most provinces that a physician with knowledge of a person who has a seizure disorder must report that person to the regional Drivers' Licensing Board for review of his/her driver's licence.

Usually, a period of one year, seizure-free, is required before the

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**Acoustic Neuroma
Association
of Canada**

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

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"The Hope is Recognition and Treatment"

Skull Base Surgery

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growing number of senior patients (over 65 yr. age group) with small tumors are being followed with no intervention. In five years only 10 percent have shown growth, leading to subsequent surgery. Hearing preservation surgery is offered to individuals with smaller tumors and serviceable hearing. The only patients currently referred out-of-province for treatment are those with bilateral tumors (neurofibromatosis type 2) where auditory brainstem implant may be performed to re-establish the hearing, should attempts at hearing preservation fail.

At UAH a monthly follow-up clinic is held which focuses entirely on patients with facial paralysis. While patients who develop facial paralysis following surgery are fortunately in the minority, with numbers continually decreasing, this group continues to require special care and attention. Sally Purdon, a physiotherapist who has undergone training in Wisconsin and Toronto, is a key member of the clinic team. She employs feedback techniques and other therapies for patients experiencing facial dysfunction, and, to a lesser degree, vestibular dysfunction.

Dr. John Keohane Jr., an otolaryngologist with special training in facial reanimation, is routinely involved with follow up. For patients with temporary paralysis, a pure gold weight is often used for the upper eyelid on a

temporary basis, and in those cases, an ophthalmologist becomes involved with the team. Follow-up imaging, employing the MRI, is done at regular intervals on all patients.

Permanent facial disruption can be eased through nerve cross-over techniques, muscle transfer, face lift, brow lift and canthoplasties (plastic repair at corner of eyelid), as well as permanent upper eyelid gold weights. UAH surgical staff perform all of these procedures.

The average tumor size presenting to this team continues to be approximately two centimeters. Therefore, the detection of tumors and the recognition of symptoms by physicians and other medical personnel remains paramount. Acoustic neuroma education is incorporated in the medical school curriculum and at continuing medical education sessions involving family and other physicians.

Educational and research activities are considered an important part of the UAH team's function. A database has been established, and recently one hundred patients who have undergone surgical removal of tumors were reviewed. The results are being compiled and prepared for publication.

The team approach for acoustic neuroma management has shown that many medical specialties involved in the 'care' of the patient are important and vital. We look forward to continuing the development of the program as time

Driving After Diagnosis

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licence can be renewed. If you do not suffer from seizures, but your judgment or your vision is affected, the physician may also recommend revoking your licence.

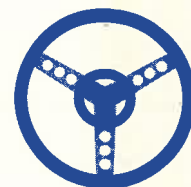
Other considerations related to your condition could affect your own personal safety and the safety of others while you are operating a motor vehicle.

When the physician recommends to you, either verbally or in writing, that you should not drive, even though you are in possession of a valid driver's licence, you must seriously consider that this recommendation

may be used by your insurance company to deny coverage in the case of a motor vehicle accident.

Insurance companies will not cover drivers suffering from impaired judgment or driving while under licence suspension.

Not being able to drive may be a frustrating experience for a person with a brain tumor. Try to arrange with family and friends to help meet your transportation needs. Discuss your frustrations and you will find most of them eager and willing to help. There can be severe financial consequences if you drive with your licence under suspension. People could get hurt.



President's Corner



Virginia Garossino

We have all heard the saying, "When life serves lemons, make lemonade." And many of us have done just that!

Because this little bit of advice hits home with so many of us, we have decided to rename our *Readers Share Hints* column to *The Lemonade Stand*. It will continue as a collection of practical suggestions, clever adaptations and stories of life adjustments - all under this banner of optimism and a good sense of humor.

Has your personal or professional life taken a new direction following your AN experience? If it was unexpected or surprising, how did

you approach it? Have you developed a new skill, travelled, changed jobs or careers? Do you look at life differently now? Have you learned a special compensation for a particular deficit? Are there products, programs, exercises, bits of advice that you have found effective?

Even a seemingly small change can be useful and beneficial to others. Please share with us!

Personally, I am constantly amazed at the resilience and creativity of our members. We are proving daily that indeed we have many recipes for lemonade!

Genetic Counselling in Family Planning for NF Parents

by Francisco Gonzalez

Because NF1 and NF2 are two major human genetic disorders, psychological and genetic counselling of affected patients and their families is an integral part of NF management.

People with NF should seek genetic counselling to discuss risks and options for managing their condition, especially if they are planning to have children. For any offspring of a NF2 patient each pregnancy presents a 50% risk of producing an affected individual. Currently prenatal tests for NF2 are available and their results may have a strong impact on the couple's life.

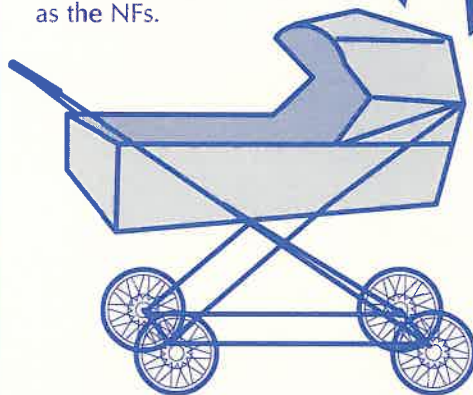
Decisions about child-bearing are extremely personal as they raise many delicate, sensitive issues. However, NF parents should be well prepared to face and manage the implications imposed by the potential or actual birth of an affected child.

Genetic counselling provides understanding of the hereditary disorder to allow the management of it. It has been defined as "a communication process which deals with the human problems associated with the occurrence, or the risk of occurrence, of a genetic disorder in a family" That process is important "to help the individual or family 1) comprehend the medical facts, including diagnosis, probable course of the disorder, and available management; 2) appreciate the way heredity contributes to the disorder; 3) understand the options for dealing with the risk of recurrence; 4) choose the course of action which seems appropriate to them; 5) make the best possible adjustment to the disorder and/or to the risk of recurrence of this disorder."

All that information may be disturbing for most people. On the other hand, such knowledge is the basis for early recognition of complications, anticipatory planning, and sound decisions about having children who may be at risk. Not only may NF be transmitted from one generation to the following ones, affecting multiple family members,

but it may also become the center of family concerns, frustrations, complications, and all the uncertainties that may result.

Feelings of guilt, depression, denial and anger may arise, and those emotions are considered to be common among individuals who are affected, directly or indirectly, by complex, incurable diseases such as the NFs.



However, such feelings do not help anybody and may represent a barrier to communication.

Genetic counselling is a helping service. It provides patients with information on the mechanisms involved in genetic disorders, such as inheritance. It also presents options for dealing with the risk of transmitting those diseases to offspring favouring recurrence. At the same time, it ensures people their right and opportunity to make a reproductive choice.

Genetic counselling is an indispensable tool in family planning for NF patients. It is up to the family to decide which approach will be the more suitable for them. Unfortunately, the individual whose life will be the most affected by that choice will not be able to express an opinion at the time the decision takes place.

The 16 Commandments of Humor (According to Humor Ink.)

"The tools & techniques to bring out your lighter side..."

- Commit to Fun!
- Schedule Fun Time
- Separate Yourself from Problems
- Do A Fun Activity
- Appreciate the Moment
- Plan to be Spontaneous
- Spend Time With People You Enjoy
- Reward Yourself
- Recognize & Reward Others
- Encourage Fun People
- Organize Group Events
- Create Challenging Work
- sevitaretIA roF kool
- KISS! (Keep It Super Simple!)
- Smile
- Just Do It!

Mailbag



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Dear ANAC,
I am still in the process of recovering from my surgery in October/93. This left me with facial palsy which necessitated a lateral tarsorrhaphy of my right eye to aid closing and to prevent excessive drying. I have facial therapy once a month at University Hospital in London and have increased movement in the right side of my face from a mere 4% after the operation to a current 47%.

Although I am feeling much better I had to quit working (I am 63). Apart from the eye and deafness problems, I am experiencing light-headedness, general fatigue, and balance problems.

I would like to hear from anyone who has made a complete recovery and how long this took. My wife has been my tower of strength throughout. She and I read your publications with great interest.

George Benbow
1026 Quinton Road
London ON
N6H 4R1

★★★★

Dear ANAC,
This is my story ... I just turned 27 years old when symptoms started. The doctor sent me to a neurologist

and had a CAT scan done. Sure enough, I had an AN tumor. I was also 7 months pregnant with my first child. I had a C-section on Sept. 20/93 and my surgery was Oct 4. I had a lot of complications. I lost the use of my right arm and leg, and had to learn how to walk again. I lost most of my hair, although it's coming back curly which means I won't need a perm! I lost my voice completely. I have facial weakness on my right side which is coming back slowly but surely. You name it, it went wrong. However, it is all coming back and I am getting better ... Thank God. If there is someone else who had a lot of complications please write.

Karen Thibert
19 Milverton Close
Waterdown ON
L0R 2H3

★★★★

Dear ANAC,
We thank you deeply for all the information you have sent us about AN. The people we got in touch with were wonderful and very supportive and I would venture to say that between your information and their support it has helped us keep our sanity.

My husband had a 2.2 cm AN removed by microsurgery four weeks ago. The surgery took 13 hours ... Thank you, Dr. Tator, for your patience and for taking the extra time to preserve the facial nerve. He is recuperating at an excellent pace and even though he is experiencing some facial paralysis, it is only temporary.

The nightmare is over and the future looks very bright.

I am returning the video so you can use it again to help someone else. Please note that I am fluent in Spanish, so if you ever need my assistance, let me know.

Again Thanks!!!!
Josefina Castro
7A Caldwell Cres.
Brampton ON
L6W 1A2

★★★★

Dear ANAC,
Thanks so much for the information concerning acoustic neuroma. The short paragraphs in the medical encyclopedias left many unanswered questions. After three months of having tests, an ABR and a CAT scan, the consensus was either acoustic neuroma or a lesion of some kind. I spent many hours reading the *Connection* and watching the videotape.

Human strength, courage and compassion filled my thoughts. The simple act of living became so important. It was an illuminating experience.

I travelled to Duluth, Minnesota for an MRI. Fear, anxiety and hopefulness were my travelling companions. I found out that my results were normal, no anomalies.

I will distribute your literature to the appropriate contact sources in Sault Ste. Marie. Please accept my donation and my heartfelt thanks for your support. I wish you continued success in your worthwhile endeavours.

Marcy King
Sault Ste. Marie ON

"Live your life each day as you would climb a mountain. An occasional glance toward the summit keeps the goal in mind, but many beautiful scenes are to be observed from each new vantage point. Climb slowly, steadily, enjoying each passing moment; and the view from the summit will serve as a fitting climax for the journey." *Harold V. Melchert*

Vestibular Schwannoma

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cortex is picked up by electrodes placed on the scalp. Several hundred brief stimuli are administered, and the responses during the first 10 milliseconds are averaged by the computer. Usually five waves are identified, and a diagnosis of vestibular schwannoma is made when some of the waves are delayed or when the time lapse between the waves is lengthened. The test takes about 30 minutes to perform in both ears and has been shown to have a sensitivity and specificity of about 90%.

There have been several reports of normal ABRs in patients with vestibular schwannoma; furthermore, the results can be suggestive in patients with retrocochlear lesions due to trauma or multiple sclerosis. Nevertheless, even very small vestibular schwannomas, including those confined to the internal auditory canal that do not even touch the brain stem, can be accurately diagnosed.

All patients whose ABR test results have been indicative of vestibular schwannoma and those whose results have been negative but who have highly suspicious symptoms and signs should then undergo MRI, preferably with an intravenous injection of gadolinium-DTPA (diethylene triamine penta-acetic acid) to increase the sensitivity of the test (there have been

no reports of false-negative test results with the use of this contrast medium). Most tumors, even very small ones confined to the internal auditory canal, can be diagnosed by means of this technique and medium, without gadolinium, MRI fails to detect a small number of them. There has been much less morbidity associated with the use of this contrast medium than with pneumoencephalography or CT with air or iodine-containing contrast media. Since MRI is more sensitive than plain CT and more specific than CT with air, it is the imaging method of choice for suspected vestibular schwannoma. Indeed, if the high cost and limited availability of MRI were not important factors, then all patients with suspected vestibular schwannomas would require only MRI for diagnosis, and the ABR test could be omitted.

The ABR test and MRI, especially the latter, are incredibly powerful techniques for the diagnosis of vestibular schwannoma. However, their power has to be unleashed by the practitioner who suspects this condition. Suspicion should be aroused when a patient initially presents with unilateral hearing loss and tinnitus. The rewards of early diagnosis are enormous, since the failure to diagnose a small tumor could make the difference between a patient who rapidly returns to work and one who needs state support for years. Furthermore, early diagnosis

and treatment is highly cost-effective, because the outcome and cost of treatment are directly related to tumor size. Moffat, Hardy and Baguley demonstrated that the costs of lifetime care for a patient with a poor result of treatment is equal to the cost of diagnostic testing for 2568 patients with unilateral sensorineural hearing loss or of surgery for 198 patients with vestibular schwannoma.

Norman Dott, a pioneer neurosurgeon from Edinburgh, advised many years ago that "the right time to remove an acoustic tumor is when it is no larger than a grain of wheat". Today, practitioners have the tests to do this.

I thank Dr. John A. Rutka, Department of Otolaryngology, Toronto Hospital, for comments on the manuscript.

Glossary of Terms

otalgia: pain in the ear

papilledema: Swelling of the optic nerve, indicates increased intracranial pressure on the optic nerve

hydrocephalus: excess water in the brain due to blockage of cerebrospinal fluid flow, increased production, or decreased absorption

nystagmus: rapid movement of the eyeballs

fundusoscopic examination: eye exam to look into the back of the eye and assess it for papilledema, done by eye specialist

Bilateral Link

by Frank Fusca

Some time ago I began to feel I was losing touch with my emotions. I would come across a funny article and read it straight through without a pause for even the slightest of grins. I'd become aware of this in the middle of the next article and wonder why I did not laugh. I'd return to the original article and read it again. Yes, it sure was funny - even the second time around!! I'd force out a "ha-ha"; but it was just that - forced, artificial and unnatural, not spontaneous as it should have been. Something similar would happen if I read something sad.

What was happening? I can't laugh and I can't cry - I have known this for

a long time and often wondered which was worse. Was this physical limitation making me lose the emotional feeling as well?

Enter Commander Data. Star Trek fans will recognize Data immediately. If you are not a Star Trek fan you still know Data, just think of him as a space-age Tin Man, a walking computer, a robot or more correctly, an Android.

Data lives in the future, in about 2350 AD. Aside from a slight greenish tinge in his eyes you would never tell him apart from anyone else. Data was designed to approximate human behaviour and he does this well, very well indeed. He is really super-human, quicker and stronger than any human. He does not require food or sleep and will not lie (unlike another friend of ours). He cannot age or feel pain.

He can perform calculations at speeds that would embarrass today's largest computers. He reads and learns at incredible rates, is always alert, calm and logical. The only Android among his peers, Data is truly exceptional.

When someone asks Data how he is feeling, he will jerk his head slightly while he performs his self-diagnostic and say, "Functioning within the established parameters". Data has no fear, no emotions, no feelings. He does have a quest though: his quest is to become human.

Unlike the many things he can accomplish so effortlessly, he knows he will never become human. This does not stop him from trying. His powerful computer circuits have

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Mailbag



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Dear ANAC,

Thank you very much for your help and kindness during our telephone conversation. I received the package of information the very next day a TRIBUTE to you and your people.

The information has been very helpful as I now face the near impossible task of deciding which method of surgery to undergo. The Doctors at one hospital want to

perform the 'SO' type, while the doctors at another hospital want to do the 'MF' type - NOT an easy or pleasant choice at all, and as of yet I still remain confused and undecided. Unfortunately I am already battling other major medical problems. Three years ago I was diagnosed as having a 'lupus-like undifferentiated connective tissue disease' and 'myalgic encephalomyelitis' (Chronic Fatigue Syndrome). I'm really not sure how I'm going to get through the trauma of 'neurosurgery', but I will - RIGHT???

I would like to make a special mention of your Toronto contact person, Catherine Hartwell. As per your referral, I called her. She is extremely kind and caring and spent a good deal of time with me on the phone. Needless to say, her support and understanding is greatly appreciated at this most difficult period in my life. I hope to speak with her again as time goes by.

I have enclosed a cheque for the 1994 membership year. The 'Association' is obviously well established, professional and well represented and should be fully supported by those whom are able.

In closing I would like to thank you once again for your kindness, and as time progresses I will attempt to keep in touch.

Stewart Kates
192 Royal Orchard Blvd.
Thornhill ON L3T 3E7

★★★★

Dear ANAC

The Tinnitus Association of Canada (TAC) is happy to renew its subscription to the Connection. Yours is a superb publication, both in quality of information and exceptionally handsome presentation. I always enjoy reading the letters you publish, they have great human interest even for someone who doesn't have an AN problem.

Congratulations on your tenth anniversary and on the excellent work done by you and the Board in sustaining the spirits of those with acoustic neuromas, as well as providing them with essential information.

Elizabeth Eayrs
Coordinator
Tinnitus Association of Canada
23 Ellis Park Road
Toronto ON
M6S 2V4

★★★★

Dear ANAC,

Please find enclosed a cheque to cover my 1994 membership. My successful surgery took place in July 1993 at Sunnybrook Medical Centre. I am back to work full time and managing quite well with one deaf ear. I feel I've had a fairly positive outcome and so would be encouraging for those facing surgery.

I greatly appreciate all the information I was able to gather prior to my surgery through ANAC. Keep up the good work!

Pat Poland
R.R.#2
Camlachie ON
N0N 1E0

★★★★

Dear ANAC,

Thank you so much for your support and thoughtfulness in sending the newsletter. Sorry to be so slow in getting around to enrolling as a member, but this past year has been a busy one. My recovery has been good and my concerns for the future are calmed by the stories of other patients.

I realize more than ever how fortunate a person is to have friends and relatives for support. And to still be able to drive is great! Thanks again.

Laura McCabe
175 Marine Drive
St. Clair Beach, ON
N8N 4K2

Maybe I Can Hear

I will go to the park
To hear children talk.

As I go further in the park
A dog starts to bark.

Children laugh and play
No sound coming from
their way.

I think I can hear them play
But I am too deaf to stay.

John Kekely
3 Storey Cres.
Etobicoke ON M9B 3C7

On January 3, 1991 John had surgery for a 2 cm. acoustic neuroma in his left ear. The surgery left him deaf in both ears although previously he had hearing in both. He dedicates this poem "to all ANAC members who lost hearing during surgery".

Informed Consent

Dona Paul Massel

Dona Paul Massel is a poet and playwright who writes about the experience, the emotion and the feeling in everyday life. By illuminating the ordinary, she evokes a response of recognition and affirmation in her readers. Massel is a grandmother and a 1990 graduate of the University of Waterloo with a degree in English. She underwent surgery for an Acoustic Neuroma in London in January of 1993. She leads workshops in creative writing and journal writing.

*She is the author of two plays and the books; **The Vikings Who Came To Fly**, London: The Third Eye Press, 1983; **Poppies For Our Sisters**, Waterloo: University of Waterloo Press, 1987. She is also the editor of **Voices From The Yellow House**, Kitchener, The Yellow House Press, 1992.*

"A brain tumor." The doctors words seem far away. "Six to eight hours surgery." Outside of me, down a long hall of denial, the words "brain" and "tumor" flash like neon exit lights. I try the doors but they are locked. "Deafness, balance problems, facial paralysis..." His words run together, flash RED! YELLOW! "An Acoustic Neuroma, small, benign. We'll go in at your temple..." my introduction to informed consent, my right to information.

Before I leave the hospital, the doctor explains the diagnosis in detail; he outlines the surgical

procedure, and he talks about the prognosis and possible complications. I see a video in which a woman with a paralysed face speaks of balance problems and deafness. A doctor talks about the eighth cranial nerve and the auditory canal. "Do you understand?" Red and yellow words. This isn't happening to me. I am handed reading material, the address of a support group, reassured and given a hospital admittance and surgery date. January 5, 1993... Whew!

Six weeks have passed and the words tumor, small and benign no longer flash red. On the contrary, they have become part of my everyday vocabulary, friends in the holocaust of less palatable words within the maelstrom of informed consent.

Of necessity, I have worn a hearing aid in the right ear for about three years. During the past summer, I noticed a dramatic increase in the silence on the one side and I went to have this checked. Several trips to doctors, a CAT scan and an MRI later, the diagnosis of an Acoustic Neuroma in the right auditory canal is made.

Within two weeks a thick envelope arrives from the support group based in Edmonton. Their newsletters detail the surgical procedures for tumors on the eighth cranial nerve. As I read, the written words echo the doctors spoken words that neon day in



London. Slow growing, 95% of these tumors are benign but if they are left, by the time they reach the size of an orange, the pressure on the brain stem causes death. My choice is surgery or death. Not much of a choice!

Are there options? Laser surgery? Still in early experimental stage in Sweden and the United States. The results show that tumors remain the same size over a two year period, but five years?? Will surgery still be required? Cost?

The reading material details the three distinct surgical approaches to the auditory canal, the suboccipital, the translabyrinthine and the middle fossa. Each approach has advantages and disadvantages. The choice depends somewhat on the surgeon, but mostly on the amount of residual hearing, on the size of the tumor and on its exact location. However, they

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Bilateral Link

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stored in them cultural information on hundreds of races. He has hobbies - he paints and plays musical instruments. He acts in plays. He has a pet cat.

Despite his efforts and vast capabilities he is often puzzled by humor, gestures, intuition or just simple human behaviour. His curiosity of human nature is often aroused and he comes up with the most thought-provoking questions. He refers his questions to fellow crew members aboard his starship. From

their discussions I can't help but feel that Data is probably the most human member among the crew.

I have become a Star Trek fan in the past few years in no small part due to Commander Data. My favourite episode was one where Data created an 'offspring'. He thought he too had the right to procreate. He named her Lal, the Hindi word meaning 'beloved'.

After initial hesitation by the captain, crew and the other children to accept her, Lal went on to have many successes. She would now refer her questions about human nature to 'father'. Data would answer as best

he could, often saying his understanding was incomplete. As Data had done, Lal was quickly earning the respect of everyone who knew her. In the end, Lal died due to irreparable damage in her neural circuits. Data and another doctor, who initially tried to take Lal away from Data, tried to save her but they fell short.

A corny story? Maybe it was. It certainly started that way, but in the end I felt very saddened. When someone now asks me how I am feeling, I am tempted to say that I am 'functioning within the established parameters'. But I know that I really do feel fine...and I tell them so.

Informed Consent

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all require prolonged microdissection because of the very nature of the tumors position inside the skull.

The auditory canal, a small hole in the skull, is the passageway of the facial, the balance and the auditory nerves. It lies behind the inner ear or two knuckles straight in the ear. Because my tumor is small, less than 1 cm, and has not yet extended into the brain, and because I still have about 25% of my hearing in that ear, the doctor has chosen the middle fossa approach. This approach is the only access that does not violate the inner ear. "Small" becomes a very important word. I may retain what hearing I still have.

The material from the doctor and from the support group fill me in on the emotional dimensions — the horrendous sense of intrusion this surgery imposes on me. Someone is going to put his hand into my head and push my brain to the side so he can poke and prod about. It is natural to feel this sense of intrusion. I am reassured about my feelings of grief. They are to be expected as I think of the possibility of my changed appearance due to one sided facial paralysis. 'I've grown accustomed to my face' as Henry Higgins so aptly said. Will it still be me in the mirror after surgery?

In vivid detail, I read about the frustrations of temporary or

permanent balance problems caused by the bruising or the removal of the balance nerve. In hindsight, I realize I already have some problems with balance, but I have become so accustomed to them that I thought they were just part of me, fuzzy around the edges.

I read of the withdrawal into the silence of deafness, of the head noises, of the dangers of leaking brain fluid, the headaches, the dry eye and reconstructive surgery if the paralysis of the eyelid is severe, of periodontal problems, of biting your cheek. Ahhhhhh! Do I really want to know?

In the past I have undergone major surgery without informed consent. The diagnosis for my hysterectomy in 1970 was couched in mumbled medical terms. When I questioned, I was reprimanded. What interest could I possibly have in the details or the outcome. He was a respected surgeon. I was a hysterectomy. Amen. Facing the unknown, I was forced to interpret my own symptoms and what I remembered of his words myself. Many trips to the library suggested to me that I had a prolapsed uterus.

I have experienced a surgeon who pouted, even threatened not to do the surgery when I refused to comply with his request for my consent to a radical mastectomy if the biopsy looked suspicious. Afterwards, he did not even have the decency to tell me that the biopsied tissue was benign. He assumed no news was good

news. I had to ask for, and wait for, this special bit of healing information.

By the time you read this I will have allowed myself to be put to sleep by a man with a knife in his hand. I will have the biggest headache I ever expect to experience in my life. And, when I look in the mirror, and I will be able to look in the mirror, I can only hope that a crooked face will add character to my otherwise reasonably symmetrical appearance.

Informed consent is not easy. It has made me look at the real meaning of each of the words the doctor used so clearly that neon day in November. There were no cliches, no put downs, no questions left unanswered. He was concerned that I fully understood the implications of what he was telling me. He was concerned about me as a person. What I experienced that day in London is an about face in the medical profession and I am cheering. About time.

When I asked "How good a surgeon are you?" he looked me right back and said "Damn good." I have every reason to believe this man because he has been upfront and truthful with me. The truth, hard as it is, is that I now see words like "small" and "benign" as a bed of roses, beside words like "chemotherapy" and "malignant." Yes, roses, just send me roses. I like salmon coloured roses, yellow roses, yes, even red roses.

Readers Share Hints

- My emotions have been very 'up and down' for a long time after surgery. There are many adjustments to make, even with minimal deficits. Having been healthy for most of my life and then to realize my body has let me down is something I have to come to terms with.

- There are definitely differences between hearing aid professionals. I recommend you ask about the person's experience with the type of aid needed for AN people and how many of them they have fit.

- One of my first thoughts after being diagnosed with AN was, "It can't be too rare, others have had it because it has a name!"

- I'll leave psychoanalysis to those who specialize in it. What it boils down to for me is: Shall I believe my view of myself, or shall I believe the view others have of me?

- I feel very strongly that anyone with a problem relating to balance should show great caution when entering the water to go swimming. Never enter the water without a companion.

ear whacks by fraser martin



reprinted with permission from Listen/Ecoute, newsletter of CHHA, Canadian Hard of Hearing Association

Hats Off to Jane Hartnett

by Ed Morrissey, Halifax Chapter member



Jane Hartnett with daughter Ashley and son Michael

Jane Hartnett has been familiar with acoustic neuroma (AN) and its after-effects for many years. As the daughter of Anna Parkinson, the Halifax Chapter contact person, she has seen the difficulties with which her mother has had to cope including the surgeries for bilateral AN which have left Anna deaf! During the past three years Jane has been part of the committee forming an association called 'Acoustic Neuroma & Late Deafened Adults Support Group.'

Her typing skills are appreciated at the chapter meetings since they are the core of the system developed for the deaf attendees. Jane types into a lap-top computer, through a special panel and the words are then projected onto the wall. In this

manner the evening's information can be read as it develops. The talks given by the guest speakers are easily understood by everyone through this method.

Although both she and her husband, Laurie, are kept busy with their two children, she also has been employed by Shell Oil Company for the past ten years. In fact, her employer was instrumental in the chapter having sufficient funds to buy the computer.

Jane, we appreciate all the assistance you are giving to us at the meetings, as well as in other ways, and we all want to say a great big, "THANK YOU" Our hats are off to you.

The Lemonade Stand

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

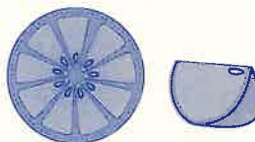
A column of personal recipes for using the lemons of life to make something more palatable.

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: I recently spoke with two women who have overcome their inability to work outside the home because of 'shortcomings' following acoustic neuroma surgery. One started taking ceramics courses several years ago to obtain more strength and control in her affected hand. She now has a small ceramic business out of her home which keeps her whole family busy.

Recipe 2: The second one is pursuing a lifelong desire to become a seamstress and has already made three beautiful bridesmaid dresses. The accomplishment included many alterations, adjustments, and lovely compliments from the young ladies who wore them.

Recipe 3: Balance Tips shared by British ANA through brochures: Check with your Hearing Therapist or Physiotherapist, as a carefully planned exercise programme may help to reprogramme balance system by giving the brain plenty of practice with the new pattern of signals. Do not turn your head quickly, as this may upset balance. Avoid bright light and sunlight; try wearing tinted or sun glasses. Balance appears to be particularly poor when you are tired or in the dark, so walk slowly and carefully, to avoid obstacles.



"Consider how hard it is to change yourself and you'll understand what little chance you have of trying to change others."

Jacob M. Braude

"Trust your hunches. They're usually based on facts filed away just below the conscious level."

Joyce Brothers



"A general practitioner? He's a doctor who introduces you to specialists."

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Making the Most of Life

Know your strengths
Acknowledge your weaknesses
Accept your strengths
Accept your weaknesses
Develop your strengths
Work with your weaknesses

L. Gray

Missing! \$35,000

For the past seven years our association has been receiving sustaining grants from Health & Welfare Canada in recognition of the valuable work that we do.

As a result of government cutbacks and reviews of all social programs, we have been advised that the grant we have been receiving may, in fact, be reduced or eliminated. At best, our grant application for the coming year will be delayed pending the review of the sustaining grant program in its entirety. You can well appreciate that the delay, if not reduction or elimination, will have serious implications on our budget and will no doubt result in severe cutbacks in our operations.

In order to continue to provide the assistance and services to our members and to the medical community, this anticipated shortfall must be made up quickly. We must therefore look to each and every one of our members to assist in our fundraising efforts. We are pleased to report that membership and voluntary contributions are at record levels. The grant, however, represents the single most important source of revenue.

More contacts with potential corporate donors are needed. Please help us by identifying corporate givers with whom you are in touch, as well as the name, address and phone number of the contact person. We have learned that success in this area can only be achieved through personal contacts.

55 Shopping Days Left 'Til Christmas

Would you like to save money on your Christmas shopping, get a tax receipt for your purchases, and have all your shopping done by tonight?

Consider a contribution to ANAC - a gift made in someone's name. An acknowledgment will be mailed to the persons you select, offering them Season's Greetings and best wishes for the New Year, and will advise them that you have made a donation in their name.

Try it and I promise you will hear only the most complimentary

comments from the recipients. All donations in excess of \$10.00 per name will be receipted for tax purposes. The amount contributed is not indicated on the acknowledgment. Let's get together and make this the best holiday season for everyone.

We have enclosed a 'gift list' to make your shopping easier.

In view of recent developments relating to our grant or lack thereof, our slogan is even more meaningful.

Jonathan A. Kantor
Director Fundraising



Get Your Share of Fresh Air

Many of the acoustic neuroma patients who suffered severe facial nerve damage, so common

only a few years ago, also have one collapsed nostril.

They only breathe half of the air to which they are entitled. Sleeping on the good side

aggravates the problem, particularly if the good nostril becomes even partially obstructed by a pillow or bed clothes.

However, a doctor recently recommended a simple device that guarantees a refreshing night's sleep. It is a small plastic device called a NOZOVENT. It is available at all Homecare & Surgical shops and some drugstores, and costs only \$12.95. This small soft plastic device worn at night keeps both nostrils

open no matter which side you sleep on, and the increased supply of air does wonders for your energy.

We urge you to try it if a collapsed nostril is a problem for you.

"There are moments when silence has the loudest voice."

Leroy Brownlow

Real Beauty Is ...

Real beauty is a smile
that starts from the heart
and spreads across the face
so wide that it overflows
onto the faces of others.

Real beauty is a heart
that seeks the good in others,
and more often than not, finds it.

Real beauty is a character
that can be trusted and respected,
so that you know there is one person
in all this world
that you can count on
when the going gets tough.

Real beauty is a vision
of the inner person
that shines so brightly
the body cannot contain it.

Real beauty is a quietness
that can be shared,
saying more than all the words
that can be spoken.

Real beauty is a face
that shows its minor flaws
without reservation
because it is certain
that those flaws
only mark character for the
loved ones
who look upon them.

Real beauty is the person,
not the facade,
because the facade will fade
but the person will always be.

And so we should concentrate
on developing real beauty
in ourselves.

The beauty that one sees in a
photograph
will disintegrate in time
and only a trace of what once
was there
will ever be left.

But real beauty is
that which can only be seen with the heart.
It is the true knowledge
of the person as a person.
It is that beauty that,
when it is there,
will radiate beyond mere looks.

(Reprinted from AboutFace, and Wide Smiles)

Special Thanks to Our Contributors

June 1 to October 1, 1994

A big thank you to all those listed below for sharing in this helpful way. Contributions are tax deductible and are promptly acknowledged with an appropriate card. Gift amounts are never disclosed.

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Box 369, Edmonton, AB, T5J 2J6

Name: _____

Address: _____

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

I am

- ☐ Acoustic Neuroma patient
☐ Family Member
☐ Medical
☐ Other

I Agree

- (Please ✓)
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

YES NO

- ☐ ☐
☐ ☐
☐ ☐
☐ ☐
☐ ☐
☐ ☐

Comments: _____