the
CONNECTION
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Just a Note from the Editor

Dear Readers,

I have chosen the topic of hearing due to the upcoming holidays. I hope that this will help those with hearing problems better communicate and their families better understand their situation.

Mona Hill

Lipreading is an Art Form

By: Beth Wilson

A typical question posed to those of us who are hard of hearing is "Can you lipread?" My response is usually, "Only if I want to get myself into trouble."

Lipreading, also known as speechreading, is an art form that is far from the accuracy that Hollywood would like us to believe. This is best illustrated by an example. I was on a bowling league last year while working on a military base. One week I was asked if I could bowl the next week against the tow trucks. At least that is what I was sure I had *seen*.

A bowling alley as one could well imagine is a terrible place to hear and the crashing of pins limits how loud a hearing aid can be amplified. I agreed to play the next week, but my curiosity drove me to the list of teams. On the lips, I saw Navy, Coast Guard, Army, and Marines among the teams. Which one looks like tow truck? Try it for yourself and we'll revisit this at the end of the article. Caution – you need a mirror for this one.

The problem is that lipreading is ambiguous. To make matters worse, once you have decided that you saw a particular phrase (such as tow truck), it is difficult to work out a suitable replacement. Even when you know the guess is not right, you feel struck and unable to find the right track. The next stage is being completely confused by the conversation you are trying to follow.

Myths and Facts

There are many myths associated with lipreading. The first is that when someone loses his or her hearing they are magically and immediately able to lipread. The truth is that lipreading is a difficult skill that few are able to master.

Another myth is that lipreading can suffice as an accommodation. Too often a hard of hearing person must fight for services because people think that sitting in the front of the room will cure all problems. The hard of hearing person will be told "you don't need an interpreter or CART (computer-assisted real-time captioning) because we have a seat in the front for you to lipread."

The truth is that lipreading can only be successful when the speaker never moves, all of the words about to be spoken are familiar to the lipreader and the words are predictable.

A little known fact is that an "expert" lipreader is guessing at two-thirds of what is said. Only one-third of speech is visible on the lips. A good lipreader must fill in the missing information. That means that the lipreader is applying a word that is known or expected to what is seen.

How it Works

One way to describe how lipreading works is by analogy to music. Music is recognized at different octaves. A song sung by an alto will still be recognized as the same song if sung later by a soprano. A piece performed on a violin will be recognized as the same if performed on a cello. Low versus high does not change the understanding of music.

Think of a chord being played on

(Continued on page 2)

a piano. The difference between a C major chord and a C minor chord is one note. If you took away the C major, the highest note in the chord, and the C minor would now sound the same.

When speech is made it can be viewed as a four-note chord. To be precise, the "notes" are called "formats" and the chords are called phonemes in speech processing literature, but we will use the words "note" and "chord" to keep things simple.

The lowest note in the chord is created by the vocal chords. Relating back to the octave analogy, a sentence spoken by a man will be understood as the same sentence when spoken by a child. The pitch of the two speakers is different but we still recognize the sentence.

The next note in the speech chord is created in the throat. The third note is created inside the mouth. The shape of the mouth and the placement of the tongue are different for an "i" and an "o" sound.

The highest note determines how sound is stopped, if at all. If the sound is not stopped, as in vowels, and highest note is lower in frequency than it the teeth stop the air. This highest note is the only sound that can be seen.

For someone who has a high frequency hearing loss, lipreading will help because it fills in the ambiguity that is heard. For example, the only difference between an "f" and "s" is that the "f" is stopped with the upper teeth on the bottom lip and the "s" is stopped with the teeth together. The first three notes of the two sounds are the same. The only difference is the highest frequency component of the speech chord where the "s" sound produces a higher frequency sound that the "f." When a person with a high-frequency loss cannot see the speaker the "s" and "f" sound the same. When the speaker's lips are visible, the difference between the "s" and "f" is clear.

If the difference between sounds is one of the lower notes and it cannot be heard, lipreading will not help. For example, the "n" and "t" look the same on the lips, but the amount of air forced beyond the tongue on a "t" sound is more than that on the "n" sound. The shape of the mouth and throat are the same for these sounds.

So when does lipreading help? For someone with a high-frequency loss, lipreading helps fill in the missing "high note" in the speech chord. Lipreading can help clarify ambiguous sounds. For someone with a more severe loss or a low-frequency loss, lipreading can help identify vowels. Lipreading can help recognize basic sounds, but not complex words. For someone with a very severe loss, lipreading will only help recognize words in context. The lipreader can only see 30 percent of what is being said.

Back to the Tow Truck

Have you figured out which team was bowling the next week? If you guessed Coast Guard, you have the right answer. If you are still not convinced, try saying Coast Guard and tow truck to yourself without voicing in the mirror. These words sound very different, but they do lipread the same.

The important thing to remember is that lipreading is hard and is an ambiguous form of communication. Lipreading can be used as a supplement for accommodations, but cannot be a replacement.

Ask any hard of hearing person about their lipreading mistakes and it becomes clear that it is a tremendous source of misunderstanding. Lipreading is an art, not a science.

(Editor's Note: This article was reprinted with the permission of Hearing Loss: The Journal of Self Help for Hard of Hearing people.)

Volunteer Opportunities on the Board of Directors

For any of you who have been thinking about becoming more involved with ANAC, there are two opportunities on the Board of Directors. One is for a treasurer and the other is for secretary or a combination of both. Commitment to ANAC is the main requirement for these positions. The technical know how is provided by our part time staff who produce the financial statements and minutes of meetings, etc. The treasurer and secretary would be responsible for ensuring these tasks are completed as well as participating in board meetings and taking an active role in the operations of the association.

Inspirations

Sylvia's Story

One year ago, I was diagnosed with an acoustic neuroma. This was a complete surprise since my neurologist was looking for multiple sclerosis. My friends all assured me that an AN tumor was the better diagnosis because the tumor could be removed, whereas MS would progress. I found this to be cold comfort.

I saw the neurosurgeon, and the options were explained in great detail. Then, I went on an assessment list to be seen by a radiologist for treatment with the Linear Accelerator in Vancouver, B. C. However, Dr. Cameron, a neurosurgeon in Victoria, B.C. felt that the tumor was too large, which meant I would not be eligible for radiation. At that time I had already been on long-term disability for ten years and was too exhausted to contemplate going to Seattle and battling the medicare system for reimbursement of treatment in the United States.

Tests with an audiologist determined that I was totally deaf. I had started to lose my hearing ten years earlier. The suspected cause was a virus infection. It was decided that surgery was my only option and a date was set for November 5, 1999. Dr. Noel would be assisting Dr. Cameron.

The time from diagnosis to surgery was only three months; in the meantime, we arranged for a bus tour and family visit to Nova Scotia. I used this period of time to spiritually prepare myself for the coming ordeal.

Surgery took 9 ½ hours. I spent a day in the intensive care unit and was then transferred to the neurological ward much too soon. I developed pulmonary edema which was very frightening, although I remember very little of this experience. I spent the next few days in intensive care. My memories include endless blood work, nausea and vomiting, and drug-induced hallucinations. It was a strange world that I inhabited for the next week or so.

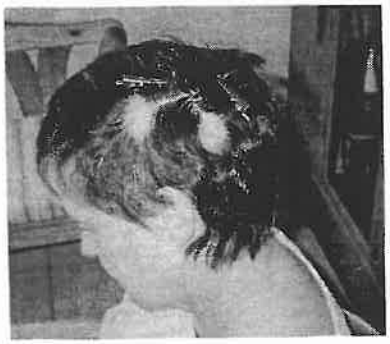
My main source of discomfort was my right eye. It didn't blink or close. The doctors had to sew the eyelid shut. I had eye drops 4 times a day which gave me relief. My swallowing and speech were additional problems, and I developed a thrush infection in my mouth. Trying to swallow was a challenge, complicated by facial paralysis on the right side. I had good nursing care, though, and progressed to a walker. Despite the mobility, I detested that walker.

Family and friends were very supportive. My husband gave me a lot of help and encouragement. My sister and friends took turns giving backrubs, foot massages and special treats. I went home on November 27th and spent a very quiet Christmas. In February 2000, the stitches were removed from my eye.

In March, we went on a three-week cruise which was a lovely part of my recovery. After our holiday, I started going to the Gorge Hospital three times a week to develop spatial skills. My perception is still not good and sometimes the right hand is a bit shaky. I am awaiting speech therapy as the facial nerve hasn't returned to full use. I now go to the gym 3 times a week, swim once a week, and feel really good. I appreciate life and all its beauty in a much different way than before surgery.

Several prayer groups kept me in their prayers. It is a time of giving daily thanks to the AN support group and everyone for all the information and get well wishes.

Sylvia Anderson
anders@pacificcoast.net



A REASON, A SEASON, OR A LIFETIME

People come into your life for a REASON, a SEASON, or a LIFETIME. When you figure out which it is, you know exactly what to do.

When someone is in your life for a REASON, it is usually to meet a need you have expressed outwardly or inwardly. They have come to assist you through a difficulty, to provide you with guidance and support, to aid you physically, emotionally, or spiritually. They may seem like a godsend, and they are.

They are there for the reason you need them to be. Then, without any wrongdoing on your part or at a n inconvenient time, this person will say or do something to bring the relationship to an end. Sometimes they die. Sometimes they walk away. Sometimes they act up or out and force you to take a stand. What we must realize is that our need has been met, our desire fulfilled; their work is done. The prayer you sent up has been answered and it is now time to move on.

When people come into your life for a SEASON, it is because your turn has come to share, grow, or learn. They may bring you an experience of peace or make you laugh. They may teach you something you have never done. They usually give you an unbelievable amount of joy. Believe it! It is real! But, only for a season

LIFETIME relationships teach you lifetime lessons; those things you must build upon in order to have a solid emotional foundation. Your job is to accept the lesson, love the person/people (anyway); and put what you have learned to use in all other relationships and areas of your life. It is said that love is blind but friendship is clairvoyant

Thank you for being a part of my life…

(source: unknown)

My Life Is Shaped By Devine Guidance To Greater Beauty

I open myself to the freedom of change. I bless the changes which come to me. Trusting in change, I relax my grip on the contours of my life. I allow new beginnings. I allow alternations, accommodation, change. I invite the interaction of imagination and possibility. I surrender agendas, outlines, plots. Recognizing that life is both active and interaction, I hold out my hand to dance, knowing that I am partnered more variably and creatively than I can yet conceive. I bless the changeable creativity of life in its unfolding.

(source: unknown)

Dare

Dare to try. Dare to love. Dare to make a commitment. Dare to take a risk

If you don't dare to take a risk, you'll never get ahead. You'll never solve your problems.

To laugh is to risk appearing the fool.
To weep is to risk appearing sentimental.
To reach for another is to risk involvement.
To expose your feelings is to risk exposing your true self.
To place your ideas, your dreams, before a crowd is to risk their loss.
To love is to risk not being loved in return.
To live is to risk dying.
To believe is to risk despair.
To try is to risk failure.
But risks must be taken, because the greatest hazard in life is to risk nothing.

The people who risk nothing, do nothing, have nothing, are nothing.
They may avoid suffering and sorrow, but they cannot learn, feel, change, grow, love, live.
Chained by their attitudes they are slaves; they have forfeited their freedom
Only a person who risks is free

(source: unknown)

HAPPENINGS!

VANCOUVER ISLAND
VICTORIA

Contact Person:
Rose Christensen
1-250-598-9693

Sept. 13/00 a three way telephone conversation took place with the committee. The Victoria Chapter will be responsible for the mailbag for the connection. It has been decided that there will be a Christmas party on December 2nd where a donation to AN will be made instead of a gift exchange.

BRITISH COLUMBIA
VANCOUVER

Contact Person:
Susan Rankin
1-250-595-0440

A meeting was held in June where information was presented about linear acceleration and its use in the treatment of AN tumors.

In Oct. guest speaker Dana Suzukovich, a registered massage therapist, talked about the benefits of message therapy for AN patients.

NANAIMO

Contact Person:
Evalyn Hrybko

A meeting was held on Oct. 21st where members shared their experiences. Some spouses where present as well. They addressed how to deal with stress.

MANITOBA
WINNEPEG

Contact Person:
Leslie Sutherland

Although no official chapter exists, a support group has been meeting for the past twelve years for those dealing with various types of brain tumors. Their meetings have been moved from St. Boniface to the Health Sciences Centre. They have found that all brain tumor patients experience fatigue.

NOVA SCOTIA
HALIFAX

Contact Person:
Ed Morrisey
1-902-434-1673
Ed.morrisey@ns.sympatico.ca

In June a social meeting was held where some members told of their experiences.

In September a member spoke of their cochlea implant. An implant is a gadget which is placed under the scalp and some wires which are set so that eventually one can hear.

SUMMARY OF THE STRATEGIC PLANNING RETREAT

The Board of the Acoustic Neuroma Association of Canada (ANAC) recently met in Toronto (November 10-12, 2000) to develop and implement an organization assessment and action plan for ANAC thanks to a generous capacity building grant from Health Canada.

ANAC focused their attention on the organization's purpose, processes and people using the in-depth performance assessment tool 'Benchmarks of Excellence for the Voluntary Sector'.

The weekend's main areas of focus were:

1. Medical Awareness: to promote efficient, effective and collaborative relationships with ANAC's Medical Advisory Board
2. Public Awareness: to make the lay public aware of symptoms of AN through a variety of mediums, and to develop a National Campaign with complementary literature
3. Membership / Peer Support: to develop and maintain the ANAC website, to update database information, and to decrease the size but increase the frequency of newsletter

The development of Provincial Contacts / Coordinators, as well as supporting local Chapters to assist the National Office in providing essential information to patients, family and friends all across Canada, was also identified as a critical component of the future of ANAC.

Communicating With a Hard Of Hearing Person

By Beth Brooks

If you have normal hearing and you live with, work with or socialize with a person who is hard-of-hearing, you already know that communication may be difficult at times. You may experience frustration in trying to make yourself understood. You may feel ignored when that person fails to respond.

It is difficult to understand what it is like to have a hearing loss, but you can learn about some of the problems that a hearing-impaired person faces. And you can learn how to communicate more easily.

PROBLEMS FACED BY A HARD-OF-HEARING PERSON

- Whether or not he/she wears a hearing aid, he/she usually hears only part of the message.
- The "gaps" in the message must be filled in by speechreading, knowledge of the subject, context and imagination.
- When these resources are insufficient, the hard-of-hearing person may feel frustrated and embarrassed.
- The strain of listening, watching, and piecing information together is tiring both mentally and physically.
- Trying to understand speech may be so frustrating that the hard-of-hearing person may withdraw from situations involving the spoken word.
- The hard-of-hearing person may feel left out and ignored by others.
- The hard-of-hearing person may not realize that someone is speaking to him/her unless the speaker obtains his/her attention first.
- Environmental factors, e.g., distance, background noise, lighting, room acoustics, and speaker characteristics make some situations much more difficult than others.

COMMUNICATION STRATEGIES

Awareness of the following points will help the quality of both the communication and the relationship between you and hard-of-hearing person.

- **Reduce background noise.** Turn off the radio, T.V., fan; close doors, windows; avoid noisy locations; help the hard-of-hearing person find a quieter location.
- **Move closer.** Speak at a distance of between three and six feet (no greater that ten feet).
- **Get his/her attention first** by calling his/her name or by gently touching his/her arm. This helps him/her focus on what you have to say.
- **Face the hard-of-hearing person directly**, giving a good clear view of your face with available lighting on your face. This will give greater visibility of your mouth movements, facial expressions, and gestures. Don't sit with your back to the window.
- **Speak clearly and not too fast.** Use normal stress and intonation. Form your words distinctly, but do not exaggerate mouth movements.
- **Do not shout.** It makes your voice unnatural and unpleasant. It also makes the vowels louder than the consonants, which can be confusing. You will also likely appear to be angry.
- **Rephrase when asked to repeat.** You will give the listener extra cues this way. For example, "I want to go shopping" is easier to speechread than "I want to go to the store".
- **Inform the hard-of-hearing person of the topic of the conversation** and alert him/her to changes in topic. Don't limit the conversation to niceties, but give the listener the information he/she needs to be able to join in.
- **Arrange furniture in a convenient manner.** No speaker/listener should be more than ten feet from any other and all should be visible. It is usually easier to hear in rooms with rugs and curtains than rooms with hard surfaces.
- **Use pen and paper** to write down key words as appropriate. Remember most hard-of-hearing people are able to speak; you are the only one who will need to write.
- **Try to be patient.** Remember that some situations are MUCH more difficult than others for the hard-of-hearing person. He/she must concentrate hard and may tire easily. Your understanding will be most appreciated.
- **Keep your sense of humour active.** Join in with the hard-of hearing person in appreciating the humor of many confusions and situations.

(Reprinted from a handout used by Beth Brooks)

PRESIDENT'S CORNER

Welcome!

As a Canadian, as a married man (to Carol), as a proud father of John, Jo-Anne-Marie, Lindsey (afflicted by an Acoustic Neuroma) and Christopher, may I state to all of you that it is an honor and a privilege to represent the Board of Directors and the entire organization.

Recently, the Montreal Neurological Hospital received approximately 216 million dollars for brain tumor research. I am sure that you and this writer welcome the news. However, if we are to attain our goals, more than MONEY is required. It requires everyone who is directly or indirectly involved with this vital organization to contribute towards the attainment of our goals—it requires us, as an organization, to solicit the understanding and assistance of 'significant others'.

Alone, I am motivated and anxious to energize this organization even more. With your assistance, understanding and support, and with the positive contributions of our membership, I am convinced that, together, we shall enact the appropriate decisions that will help us to be an effective and efficient organization.

I would like to take this opportunity to remind you of the objectives of ANAC

ARTICLE 3 - OBJECTIVES OF THE ASSOCIATION

3.1.1 To provide support and information to individuals who have experienced acoustic neuromas (schwannomas) or other benign tumors affecting the cranial nerves.

3.1.2. To furnish information on patient rehabilitation to physicians and health care personnel interested in the treatment of benign tumors and the alleviation of post-surgical complications.

3.1.3. To promote efficient, effective and collaborative relationships with ANAC's medical advisory board.

3.1.4. To respond to Members' non-medical needs.

3.1.5. To encourage research into the diagnosis and treatment of benign cranial nerve tumors.

- - and now my request

Within one month, please forward the following to Cheryl Bauer, our National Coordinator:

ANAC
P.O. Box 369
Edmonton, Alberta
T5J 2J6
FAX-780-438-4837
e-mail anac@compusmart.ab.ca

Request # 1- regarding the included (5) objectives, please list the one that is most important to you as #1, then 2nd (#2), etc.

Request # 2 - Please indicate one or two objectives that you think that I, as your President, and the Board should devote our fullest attention to. (It may be one or two that are not covered by the objectives).

Before concluding, I wish to convey to Peggy Bray, (Past President) and Glyn Smith (Past National Coordinator) a simple but genuine 'thank you'. Thank you for your positive contributions and all of your efforts that convey your belief in the practice of social responsibility. Your successes will encourage me to strive for future successes.

For the confidence that has been conveyed to me, I welcome, accept and thank you for this opportunity to work for and with you.

Sincerely,
Dr. John Oss
President ANAC

Thank You !

I want to thank all the members and friends of ANAC for the steadfast support I received during my term as your President. Your commitment, enthusiasm and positive attitude made the difference as we worked to steer our Association in new directions, and it was definitely a team effort. The road may have been bumpy from time to time, but we have been able to successfully move forward.

With your positive community spirit, the leadership abilities of John Oss, our new President, and the dedication of Cheryl Bauer, our new National Coordinator, the future looks bright. I'm confident that the Association will thrive on both the opportunities and the challenges that lay ahead.

I look forward to sharing the knowledge and experience I've gained with you and the Board of Directors in the coming months.

Cheers,
Peggy Bray
Past President

Dear Mailbag,

Cleo has been my constant and faithful companion since 1989. She is a professionally trained signal (hearing) dog, trained by Pacific Assistance dogs Society.

After having a 15.5 hour surgery for an acoustic Neuroma on October 6, 1981, I was left deaf in my left ear. I could not locate where sounds were coming from (the warning signal) and it was difficult to discriminate what I heard.

When Cleo came to live with me I felt more confident and secure; I felt less tired because I relaxed, letting Cleo do her job. Cleo and I have had a partnership of trust and love that has allowed her to help me live an independent and productive life.

After my surgery I remember joking with my family that I need a hearing ear dog. I had no idea such a thing existed. I only knew there were seeing eye dogs. It was when I was working with an employment rehab. Counselor from the Dead and Hard of Hearing Association in Vancouver that she mentioned she had a 'hearing dog', and I knew with a certainty, I wanted one too. I was put in touch with P.A.D.S., and they sent me an application form. My application was assessed and granted. They felt a signal dog would make my life easier.

Then came the call from P.A.D.S. They had a dog they felt would be a match for me. Would I like to meet her? Indeed, I would! I'll never forger the day Cleo pranced down my long driveway to be introduced to me. She had undergone extensive training and could respond to 4 signals: the telephone, the doorbell, the smoke alarm, and the fire alarm. It was now my turn to be trained to work with her. I took a week off work and the trainers and Cleo and I worked (it was like 'boot camp') from 8-4 for 5 days.

I became a recipient of a hearing dog. We have been together now for 11 years and it has been a match mace in heaven. I requested she be retired last October because she seemed to be getting very tired after a shopping trip or an excursion on the bus. In June of this year, I noticed a large tumor growing above her left ear and her hearing seemed almost gone. She was diagnosed with an aggressive type of cancer, and treatment was not recommended. We visited the vet last week and Cleo is hanging in there. Her stamina is not what it used to be. We can't go for 5 mile walks anymore, but a walk around the block brings a puppy spark in her walk. Every night, we cuddle and say goodnight – grafetul for another day together. There is no question in my mind that 'dog is man's best friend'. Thank you Cleo.

Pacific Assistance Dogs Society can be contacted at 9048 Stormont Ave., Burnaby, B.C. V3N 4G6 Telephone (604) 527-0558, or www.wzone/showcase/pads.

If you have any question for me, you can reach me at (250)598-9693 or write me at Rose Christensen, 1785 Emerson St., Vitoria, B.C., V8R 2C2.

Dear Mailbag,

It has been nine years now since I have had the insertion of a gold weight under my eyelid. I want to share that this has been a big help to me, giving me about 25% more protection from the elements of the air (wind, rain, sunshine, dust, and smoke). If you have a wide open eye post AN surgery, I recommend you look into this procedure yourself. You would go to your GP and ask to be referred to an opthalmologist.

In the past two years I also have had a silicone pug inserted in my lower tear duct (giving 70% more protection) and later one inserted in my upper tear duct (30% more protection). Sometimes we do not know of these available procedures until we read of them in the Connection.

If you have any questions regarding eye care, you could contact me, Evalyn Hrybko at ehrybko@oberon.ark.com or call 250-282-3269

Dear Mailbag,

My AN is being monitored and because it was relatively small, Dr. Tator advised me about 5 years ago to leave it alone. When I moved to London, Ontario, I became Dr. Parne's patient. So far it still hasn't grown and my next MRI is in 2002.

However this doesn't mean that all is well ! My hearing in my left ear is giving me a lot of problems. My balance isn't so great either and I can't walk a straight line. Somehow though we all learn to cope !!!

I would be interested in any information at all that may be available from other people diagnosed with AN who are being monitored?

My big question is: Has anyone found a hearing aid that helps them? I have spent the last eight months trying to obtain a suitable aid, and

(continued on page 9)

I've had problems with feedback, constant static noise and shushing background sounds on each one of them! My hearing loss is in the high frequency level , and my audiologist just doesn't know what to do with me anymore because I've tried about eight different aids. In the ear and behind the ear aids just don't seem to produce a clear sound for me, and I am so frustrated and upset because of eight months of appointment after appointment. Has anyone else had this problem?

I sure would like to know someone I could talk to who is going through and/or had the problem resolved.

Thanks very much,

Edna Ferguson
42-70 Sunnyside Dr.
London, ON N5X 3W5

Dear Mailbag,

'It could have been worse', how I hated those words from the well-meaning visitors and family - 13 years ago - a 15 hour operation later with deafness, a crooked face and bulging eyes. My beauty gone forever and more. What could have been worse?

Well it was a bout with chicken pox 3 years later at the age of 40 that finally made me realize that my 'crooked face' and my 'surgically altered eye complete with a gold implant' wasn't that bad when I considered living with hundreds of 'pox' scars on my face for the rest of my life. It was then that I made a vow never to grumble about my crooked face again as long as these 'pox' welts disappeared - they did and I kept my promise.

It took a long time to accept the reality of my life after an AN, but I finally got there and 13 years later I am okay. I still can't blow up balloons, climb a ladder, walk a straight line in the dark, locate the person calling out to me in the food fair in our local mall without spinning in circles. And most importantly I cannot listen to my favorite CD in stereo but, I am still a very rich person. I have a husband and family who love me, and my health has been pretty good...I have learned to adapt...I always sit in the right position to line up my hearing properly and I sleep on my good ear so as not to hear my husband snoring (a great unexpected benefit and bonus). I use my eyes more to locate things rather than my hearing and it's honestly not until someone asks 'did I have a stroke' or laugh uncontrollably at something very unexpectedly funny that my face really pulls to one side or I slurp coffee on a new blouse when my mouth fails me... that I remember the pain and sadness of my physical losses but, it's only fleeting.

Life is just fine, I have come full circle, apart from the soar neck that I have suffered with since the surgery, which has now been relieved by the magic hands of my message therapist (I pamper and treat myself to a message every two weeks). I am now only irritated and hindered by my memory. I am terrible, I interrupt conversations and completely lose thoughts in my head. I think it is my age, I am pushing 50, but maybe it's just another side effect of my AN. I would dearly love to get to get to the bottom of this memory loss mystery.

I have had cat scans every five years. After 15 years my doctor says I can forget about this whole thing if all is clear at that time - forget - never - go on - most defionately. I'm looking forward to life again, places to travel and grandbabies yet to be born. My motto on life is: 'Don't think about how bad it was... think how good it will be... and is.

Elaina Wugalter

If you have had an exceptionally positive experience with a medical professional and would be willing to share your experience. Please contact our office.

OR

If you have something for the mailbag please feel free to contact us at:

ANAC
Box 369
Edmonton, Alberta
T5J 2J6
780-428-3384
1-800-561-ANAC (2622)
anac@compusmart.ab.ca
www.anac.ca

NF2 News - Welcome

Well, I guess it's about time I introduce myself to the AN community. I am Jason Chartrand, and I am pleased to be the new NF2 contact for the ANAC. I was going to use this (limited) space to talk about myself, but I don't think I 'll do that.

Along with many NF2ers who are online, I have joined the NF2 Crew. I think I would have been lost many times over if I had not had the support of my fellow crewbies. In the past few months, though, we've had to say good-bye to a few of our friends who reached the end of their journey with NF2.

John Petito was quite (in)famous among the NF2 community. For NF2ers the NF2 Review may have been the only thing helping them keep their sanity. John started the Review in the hopes of bringing good news to people with NF2, and uniting the NF2 community. He devotedly put out issue after issue of the Review. Sadly, John is greatly missed since passing in April 2000.

Recently, the NF2 Crew has lost other crewbies, young crewbies. Donald Grim passed away in September, 2000. Don often entertained his friends with his humorous ways. Don was closely followed by Tracey McCarthy, who was a relative newbie to the crew.

I am not trying to depress anyone, but it is important for people to know that there is a lot more to NF2 than acoustic neuromas and deafness. By the same token, there is a lot more people with NF2 than NF2. In my coming articles, I'll hopefully be able to introduce you to some of my favourite NF2 people.

I am available for contact through email at nfres@hotmail.com, or TTY/FAX at (780) 439-0191.

THE "AN" EXPERIENCE

How AN Can Affect Family and Friends

Over the years, while chatting with AN people, I have realized that what they are going through has affected those who are near and dear to them. The changes that come into peoples' lives are not all negative. The experiences I am sharing, my own and others, are reflections on going through a health issue, learning in time to appreciate everyday little things, and putting less emphasis on monetary and worldly attitudes.

Short term memory problems can cause frustrating misunderstandings and make for challenging relationships.

Fatigue seems to be ever with us, especially in the early months after AN treatment. Along with fatigue is the fact that we can no longer do all the physically strenuous activities we may have done previously. This would affect family members in changing patterns of shared time. Some AN people can no longer work full time, or at all. Some give up driving and, therefore, need assistance with routine responsibilities: banking, grocery shopping, getting to appointments, etc.

One complaint/comment I hear from AN people is the major adjustments to one-sided hearing, and the loss of directional sounds. It can certainly be embarrassing and even exhausting in public settings.

In some cases where balance is a big problem, AN people may now need extra devices in the home, such as handrails along stairways and in the bathtub. Someone needs to install these safety devices.

Personality changes are related to these adjustments. Many AN people become less independent and less confident in themselves. These issues definitely affect family and friends who may not understand the invisible struggles that are required to cope with hearing loss. Feelings of disorientation and avoidance of noisy, crowded places may be life altering for socially outgoing AN people.

Yet, we need to realize how much we need each other when going through life's traumas. Let's be positive and remember to share and care for each other. I encourage you to share your experiences in a letter to the "Mailbag" for *The Connection*. Thank you.

Evalyn Hrybko

Leave a Legacy

Leave a Legacy is a community based effort to encourage people from all walks of life to make a gift to not-for-profit and charitable organizations.

It is very easy to arrange for a gift. The most common way is to make a charitable gift through a bequest in your will. This can be done by setting aside a specific amount, a percentage of your estate or by donating an asset such as a car, boat or home. Another approach is to leave a paid up life insurance policy, securities, retirement account or other financial investment. Many of these approaches can result in tax savings for your estate.

If you are interested in Leaving a Legacy please consider the Acoustic Neuroma Association for your gift. You can get help from local Leave a Legacy programs or work with a professional advisor such as a financial or estate planner, lawyer, accountant, trust office or insurance agent. A professional advisor will help you to maximize your tax savings.

Other information can be obtained by visiting the Canadian Association of Gift Planners web site at www.cagp-acpdp.org. If you have no other source of information but would like to leave ANAC a gift (or consider it) contact the National Office who will try to put you in touch with an appropriate person or organization.



Christmas Gift Dilemma?

Don't know what to buy for that person who has everthing?

No need to fight the crowds at the mall, no tired feet, no last minute rush. Give a gift that will really count!

Make a donation, in their name, to ANAC or buy them a membership ($32 for one year)

It's quick and easy. For donations of $10 or more you will receive a tax receipt, the Association will send your friend a Christmas card notifying them that a donation has been made in their name (and by whom) or, informing them that a membership has been purchased in their name and by whom.

All donations and membership requests must be received prior to December 16th to ensure that Christmas cards will be delivered on time.



We also have a some merchandise available which is listed at the back of the Connection. So please show us your support.


Instructions for Life in the new millennium.

1. Take into account that great love and great achievements involve great risk.
2. When you lose, don't lose the lesson.
3. Follow the three Rs: Respect for self, Respect for others, and Responsibility for all of your actions.
4. Remember that not getting what you want is sometimes a wonderful stroke of luck.
5. Learn the rules so you know how to break them properly.
6. Don't let a little dispute injure a great friendship.
7. When you realize you've made a mistake, take immediate steps to correct it.
8. Spend some time alone every day.
9. Open your arms to change, but don't let go of your values.
10. Remember that silence is some times the best answer.
11. Live a good, honorable life. Then when you get older and think back, you'll be able to enjoy it a second time.
12. A loving atmosphere in your home is the foundation for you life.
13. In disagreements with loved ones, deal only with the current situation. Don't bring up the past.
14. Share your knowledge. It's a way to achieve immortality.
15. Be gentle with the earth.
16. Once a year, go someplace you've never been before.
17. Remember that the best relationship is one in which your love for each other exceeds your need for each other.
18. Judge your success by what you had to give up in order to get it.
19. Approach love and cooking with reckless abandon.

Please Donate

To Fellow ANAC Members:

As funding is a major issue within our association I thought I would send in this little note to let you all know about two areas of contributions that you may not be aware of.

Most cities have United Way campaigns and the public is not often aware of an option offered by the United Way, which is a 'give to – give through' option. When you fill out your United Way pledge form, on the back of the first copy you are given the option of specifying which organization you want your contribution to be sent to. You can specify an organization under the United Way umbrella in your area or any registered Canadian charitable organization. Next time, why not specify ANAC?

Another option that I have available to me through my employer is a Matching Gift program. This program enables employees of my company to send a personal donation to the charity of their choice and then apply to the company to 'Match' the donation. The company I work for has a specific yearly budget for this program and the funds are usually spoken for early in the year as many staff members like to use this option to raise extra funds for their favorite charity. There is usually a restriction on the amount that the company will match for any one staff member, but every donation helps. Please check with your employers to see if they have anything similar in place.

Thanks,
Leslie Sutherland
Winnipeg, MB

Special Thanks to Our Contributors – June 1, 2000 to October 31, 2000

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Websites

http://anausa.org/
The Acoustic Neuroma Association of the United States

http://home.ptd.net/~tonyc/anstor.htm
An Acoustic Neuroma story page

www.anarchive.org
Facts about Acoustic Neuroma

www.uinspire.com/hom.asp
Daily Inspirations

www.anac.ca
Acoustic Neuroma Association of Canada

www.tinnitusrelief.com
Tinnitus Relief Center

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Contact for Special Areas

NF2 CONTACT
Chartrand, Jason
11028 – 84 Ave
Edmonton, AB T6G 0V7
780-439-0191
jchartra@westerncanada.com

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

PROVINCIAL CONTACTS

ALBERTA
Patricia Greenwell
5302 57 Street
Ponoka, AB T4J 1M4
403-783-4257
kgreenwell@ccinet.ab.ca

SASKATCHEWAN
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329 Sackville Street
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50 Wimpole Dr
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Acoustic Neuroma Association of Canada

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Need more information or assistance? Please call us.

NAME:_____

ADDRESS:_____

TELEPHONE:_____ FAX:_____

EMAIL:_____

Please indicate any changes, additions or corrections to your personal information

MEMBERSHIP:

☐ New Membership $32 ☐ Renewal $32 ☐ Gift $32

If this membership is a gift (name and address)_____

If you are a new member, are you:

☐ present/former patient ☐ family member ☐ friend

☐ medical professional (specify)_____

☐ other (specify)_____

Willing to share your name with other patients/recent diagnoses: ☐ willing ☐ not willing
Willing to give help locally when needed: ☐ willing ☐ not willing

DONATIONS:

☐ Gold Circle ($1,000 or more) ☐ Silver Circle ($500-$999) ☐ Bronze Circle ($300-$499)

☐$200 ☐$100 ☐$50 ☐$40 ☐Other $_____

Make my donation: ☐ General ☐ In honor of ☐ In memory of

Individuals name_____

Send Card to (name, address):_____

PRINTED MATERIALS & MERCHANDISE: (see over for order form)

PAYMENT TYPE:

☐ Please find enclosed a cheque or money order, payable to *'ANAC'*, for $_____

☐ Please bill my Visa Card #_____ Expiry:_____, for $_____

Signature:_____

Tax receipts are issued for all donations over $10

Your Gift Means We Can . . Find it, Treat it, Beat it!

THE NEED
For those dealing with acoustic Neuroma, and their families, information and support are needed. These people rely on the Acoustic Neuroma Association of Canada (ANAC).

We rely on the generosity of our members and other supporters in order to provide this help. Membership fees alone, valuable as they are, cannot finance the organization, so we still need donations from individuals like you.

YOUR GIFT *(Charitable Registration #11877-7168)*
Be assured that any gift will be useful to the fullest. You will have the thanks of all people associated with the Acoustic Neuroma Association of Canada, and you will be recognized as a donor in *the Connection*. Revenue Canada also recognizes your gift as a tax-deductible charitable donation.

Should you wish to make a donation, please fill in the appropriate details on the other side of this page.

Your donation will be used where it is needed most. Some possibilities are:

1. the Connection newsletter
2. toll-free patient support telephone line
3. the ANAC website
4. publication and distribution of printed materials
5. public awareness and promotion
6. development of local chapters / support groups

PLANNED GIVING
Should you wish to consider a larger gift of property, shares, annuities, insurance or cash, please contact the office for more information on planned giving (tel 1-800-561-2622 or e-mail anac@compusmart.ab.ca)

ANAC MERCHANDISE (with logo)

Coffee Mugs	quantity ____	$ 3.00 ea or 2/5.00
Baseball Caps	quantity ____	$ 8.00 ea. or 2/15.00
Sweatshirts (royal blue, L only)	quantity ____	$ 25.00 ea.
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ANAC
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