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**A Publication
of the Acoustic
Neuroma
Association of
Canada**

**Association
pour les
Neurinomes
Acoustiques du
Canada**

www.anac.ca

President's Message

I was elected as President of the Acoustic Neuroma Association of Canada two years ago. The Board of Directors was commissioned with executing the goals and objectives of the Strategic Plan and remained enthusiastic and focused throughout the entire process. The establishment and implementation of the identified strategic priorities were made possible through strong, consistent support and commitment of ANAC members, stakeholders, donors, teams of volunteers, our Board of Directors and National Coordinator. I am proud to report, on behalf of the Board of Directors, that almost all of the goals and objectives were accomplished. The rest are currently in progress with scheduled timelines. After two years of intense work, ANAC is now in a much better position to realistically look forward to 2014 and beyond.



Dr. Carol-Anne Sullivan

The ANAC Board continues to strategically aim for diversity; comprising of unique individuals with backgrounds that are advantageous and necessary for advancing and promoting ANAC's priorities and maintaining organizational governance.

Once again, I encourage those who are not yet members to join and to those who are already members to spread the word. Membership is open to anyone who has been affected by an acoustic neuroma and/or is interested in supporting the goals of the organization and becoming actively involved in our efforts. We also have Board of Director vacancies – please feel free to contact our National Coordinator to find out more about it.

As always, I'd like to express my profound gratitude to our members and non-members, stakeholders, donors, our National Coordinator, Board and Committee Members and our strong and devoted teams of volunteers for their hard work, insight, innovation, and spirit of teamwork.

Finally, in closing, after careful thought, I have decided not to renew my term as President of ANAC and to step-down from the Board of Directors at this time and focus

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The Acoustic Neuroma Association of Canada provides information on a wide range of health and medical topics. While due diligence in collecting and reporting the information was followed, the Acoustic Neuroma Association of Canada does not warrant the accuracy of such information. The information contained herein is not intended to substitute for the advice of a physician, and you are advised always to consult your doctor for specific information and personal health matters. Unless otherwise specifically indicated, the naming of an organization, product, treatment, or therapy in this publication does not imply endorsement by the Acoustic Neuroma Association of Canada.

Your comments, ideas, suggestions, and financial support are needed and welcomed, and may be direct to:

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T: 1-416-546-6426
F: 1-705-657-2365
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Website: www.anac.ca

on another passionate and important cause: developing a toolkit and online forum specifically for *caregivers* of traumatic brain injured survivors. It has been a sincere pleasure serving and leading ANAC; a privilege I will never, ever forget.

Carpe diem and farewell!
 Dr. Carol-Anne Sullivan

Medical Advisory Board

Members Corner: Dr. John Rutka

Dr John Rutka is a professor of Otolaryngology-Head and Neck Surgery at the University of Toronto. He is involved in the multidisciplinary medical and surgical care of patients with vestibular schwannomas (VS) at the University Health Network. His specific areas of interest include the effects of tumors on the vestibular (balance) system. His clinical research has focussed on the conservative management of patients with VS's.



2013-2014 Medical Advisory Board

Dr. Gelareh Zadeh, Chair
 Dr. David Roberge
 Dr. Anthony Kaufman
 Dr. Igor Barani
 Dr. John Rutka
 Ms. Joanne Dorion

Exclusive to ANAC Members

Multi-Disciplinary Team (MDT) reviews, conducted by Dr. Gelareh Zadeh,
 Chair of the ANAC Medical Advisory Board

MDT Reviews can be requested through a family Doctor referral

For further information, please contact the National Coordinator

Board of Directors News

Farewell from Mary Lou Glazier

Hello and Good-bye to all ANAC Members and Associates.

On September 30, 2013, I formally resigned my seat on the Board of Directors to which I was elected at the AGM in the fall of 2011. Previous to that position, I was elected President of ANAC at the AGM in Vancouver in September 2009. My daughter Cheryl is an acoustic neuroma patient and had her surgery in Vancouver in April of 2004. Although she resides and works in the Nation's Capital, I was able to make arrangements for her to have her surgery at Vancouver General Hospital. I was also able to get her referred to the Best in the West ANAC Team of surgeons, Dr. R. Akagami, Dr. B Westerberg, and their associates. They had recently developed the Evoked Motor Potential Procedure for monitoring the 8th cranial nerve throughout the entire surgical procedure; in Cheryl's case it was 12 hours. She has been monitored since that time but her only loss was hearing on the affected side. There was no damage to her facial nerve. For this, all of our family members are eternally grateful!

Thus it was at my first AGM conference with my daughter Cheryl when I was nominated and elected to serve as President of ANAC for a one - year term. I am a retired Regional Coroner for BC and also a Retired Critical Care Registered Nurse, thus this new volunteer position posed some logistical problems, namely conducting Board Meetings by Conference Calls. I spent a great deal of "retired" time wading through the previous year meetings and getting to know the other Board Members. I was re-elected the following year and decided that I would serve one more year and hopefully we could find another Presidential candidate by the next AGM, which we did. We were so fortunate to welcome Dr. Carol-Anne Sullivan as our President in 2011 and as you all know, she made some major inroads with ANAC and was instrumental in developing the Strategic Plan. We asked for reasonable time commitments from our Board of Directors, several of who were brand new Directors. I saw a significant improvement in the functions of ANAC when the President and several Board Members were all located in the Toronto area. This made it much easier to get things done.

I am very pleased that I had the opportunity to assist ANAC for the past four years, and I will continue to be a Member and also a volunteer to Theresa, our National Coordinator for all things "Vancouver" and also as a contact for related medical issues if needed. I wish all of you the very best!

Best regards to all,
Mary Lou Glazier (formerly Merner)



Left to Right: Dawna, Mary Lou and Cheryl

Board of Directors News

Meet ANAC's Newest Board Members



Lyna Newman, FCIP, CRM, CHRP

Lyna brings a broad spectrum of experiences both in the positions she has held and her professional and community leadership. Since 1989, Lyna has worked in the insurance industry most recently Vice President, Human Resources and Operations with RRJ Insurance Group. She has been involved with strategic recruiting, developing & facilitating training programs, managing staff, conducting performance reviews, budgeting, succession planning, strategic planning and compensation. Her responsibilities in Operations included streamlining workflows, using technology to improve productivity, quality control and governance.

Lyna holds a number of professional designations including:

Fellow, Chartered Insurance Professional (FCIP); University of Toronto

Certified Risk Manager (CRM), University of Toronto

Certified Human Resources Professional (CHRP), Toronto

From 2001 to 2011, Lyna joined the Board of Directors for Women in Insurance Cancer Crusade (WICC), a charity whose mission is to raise funds to support cancer research, exclusively for the benefit of the Canadian Cancer Society (CCS). In the early years, she assumed the position of Executive Director where she established numerous operational procedures for this fast-growing charity. With the help of a passionate board of directors and volunteers, this not-for-profit organization grew from grassroots to having raised over six million for the CCS and expanded into four provincial chapters with several other fundraising efforts across Canada. Lyna facilitated the incorporation process and financial oversight, was instrumental in centralizing processes, creating accounting procedures, the development of the website and guidance to the various Event sub-committees. WICC honoured Lyna with the "Lew Dunn Award".



Melanie Monaghan

My name is Melanie Monaghan and I will be involved in Public Awareness for your organization, the Acoustic Neuroma Association of Canada.

I became interested in acoustic neuromas when I volunteered with a four-year-old boy at a local preschool program that serves deaf, hard of hearing children and CODA children (Children of Deaf Adults). He had a condition that involved bilateral neuromas and as a result was profoundly deaf and used American Sign Language to communicate.

Meet ANAC's Newest Board Members continued

I am also profoundly deaf and use cochlear implants. Partly because of my own hearing loss, I have an interest in this field. I completed my bachelor's degree in Psychology in 2011 and hope to eventually take my masters of Audiology studies. In addition to my educational experience, I am currently volunteering at the aforementioned preschool program, a geriatric psychiatric ward at a local Hospital, and working as a research assistant on a cochlear implant and music perception project. I hope that my lifelong experience with hearing loss, educational and volunteer experience will be an asset to your organization. I look forward to working with you in the role of Public Awareness.

Please join us in welcoming Lyna and Melanie to the Board of Directors for the Acoustic Neuroma Association of Canada. We will greatly benefit from your professional experience and community leadership involvement.

Interested in a position with ANAC's Board of Directors?

There is currently one Director position open on the Board of Directors

Primary Responsibilities Include:

- ✓ Preparing for and attending monthly board meetings
- ✓ Leading and performing committee work, as necessary
- ✓ Attending board training and the bi-annual AGM if possible
- ✓ A two year term commitment, with approximately 8 hours per month

Candidates for consideration will have a broad range of skills and experience. Ideally, we are looking to augment our skill-set with candidates who have experience in marketing, grant / proposal writing, medical knowledge / research or previous not-for-profit experience. If you are interested in joining the Acoustic Neuroma Association of Canada's Board of Directors, please contact the National Coordinator for further information at info@anac.ca or call 1-800-561-2622

2013-2014 Board of Directors

Executive

Chris Grant, Vice President
Americo Meneguzzi, Treasurer

Directors

Cora Hannel-Greer
Dr. Gelareh Zadeh, Medical Advisory Board Chair
Jennifer Wong
Linda Steele
Lyna Newman
Melanie Monaghan

Greetings From The National Coordinator



The National Office has been busy the past few months with many patient inquiries, memberships renewals and changes to ANAC's Board of Directors.

As we at ANAC have been welcoming our newest board directors, we are also saying farewell to Carol-Anne and Mary Lou. Both women have contributed their exceptional skills and many hours to the success of ANAC. I wish them all the best with future endeavours.

I am happy to report, ANAC has partnered with Red Deer College in Calgary and Algonquin College in Ottawa to provide practicum opportunities for students in the Virtual Assistant Programs. Students will be involved with updating manuals, newsletter research, and the development of social media and Learning Management System materials. Please watch for further updates on this partnership.

On another happy note, ANAC's Articles of Continuance were granted by Corporations Canada in October. Thank you to all members for your patience over the past couple of years while the Board of Directors and National Coordinators worked to organize this process.

Last month, I was fortunate to meet via teleconference with ANAC's Chapter Leaders. I was impressed by the years of experience, dedication and compassion that is held by these individuals, true leaders indeed. Through this meeting we discussed the many strengths and some areas that need improvement to continue our support to AN patients. I look forward to implementing and developing resources with them in the months ahead.

Thank you to everyone who submitted your vote of approval to not hold an Annual General Meeting in 2013. The Special Resolution passed with well over the required two thirds votes. I will be corresponding with members in the next couple of months with details regarding the 2014 Symposium and Annual General Meeting.

To promote ANAC's services and connect with people diagnosed with Acoustic Neuroma, I have been diligently working to include ANAC in the many community services directories across Canada. Directories are often utilized by professionals and patients seeking support services. If you would like ANAC included in a directory in your community, please contact me with details.

Thank you, to everyone who has sent notes of encouragement and support, as I have transitioned into the National Coordinator position over the past year. Your kind thoughts and guidance are greatly appreciated. Your feedback is always welcome.

I look forward to working with you as we move into the 2014 year,
Theresa



A Whole New Normal

By: Marla Bronstein

Shortly after being diagnosed with an Acoustic Neuroma in 2009, I learned of a national symposium taking place in Vancouver BC, about 80 miles from my hometown, Bellingham, Washington. Driving north that morning, I found myself waiting at the border crossing, which gave me time to think.

40 years earlier, my grandmother, who was then in her 60's, died from a brain tumor. The doctors said it was cancer. (I don't know how they could tell back then. I'm not sure their equipment was sensitive enough to tell the difference between a cancerous tumor and a benign one.) They were absolutely sure it was in a place they could not reach surgically. The doctors treated her for cancer with radiation and chemo. She lost her hair, lost her balance, and within six months of her diagnosis, she lost her life.



Ten years after my grandmother died, I began my personal experience of years of physicians minimizing, ignoring, denying, and explaining away my ear-related complaints and symptoms. Until finally, when I was in my 50's, a doctor listened and scheduled me for an MRI.

I received the unexpected diagnosis. Brain Tumor. Acoustic Neuroma. It made sense. It justified the ringing, earaches, loss of hearing, all only in one ear. It substantiated the years of balance issues, the vision concerns. (And the radiologist was 99% sure it was not cancer.)

From that moment, my treatment journey took on a life of its own. I spent hours on the internet, reading stories, watching post-surgical videos posted on YouTube. I found the Acoustic Neuroma Association, (ANA) joined and started reading everything I could find about this thing in my head.

Some survivors had insufferable headaches. Some walked with a cane. Some suffered severe facial nerve damage, and needed additional surgeries.

I didn't know what to do, and I didn't know how to decide what to do. I need instructions, a road map, to help me maneuver through the information overload I was getting.

Those who suffered no visible signs of this surgery, those who had no facial nerve damage were silent. Except for one. Adrienne reached out to me, she lived across the Canadian border, had just had her surgery, and she was planning to attend the symposium of the Acoustic Neuroma Association of Canada that was taking place a few weeks later in Vancouver, BC. She invited me to come up, and to meet her.

It could not have been more perfect.

I arrived at the symposium, met physicians, physical therapists, hearing aid representatives, and Adrienne. After meeting her in person I found hope and encouragement in the midst of fear and apprehension.

A Whole New Normal... continued

I started regular journaling online, which enabled me to share information with my friends and family, and I only had to “say it” once. So many thoughts were going through my head, and journaling forced me think rationally. It also allowed me to get the fear and anxiety out of my head so I could function on a daily basis. Five months later, I had my surgery, and started my “new normal.”

I was encouraged to edit the journal into a memoir, to make my story more easily available to others who were looking for information with a positive outcome. My dream is that physicians will provide copies to newly diagnosed patients, to give them hope. And I hope more people with good outcomes from surgery will share their stories as well.

In a perfect future world, Acoustic Neuromas will be diagnosed earlier, which will result in a greater number of positive outcomes.

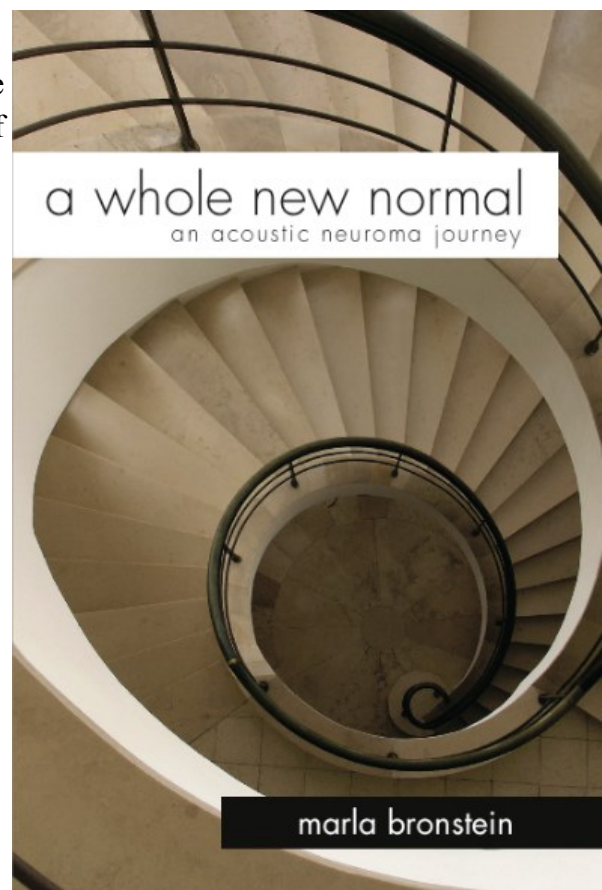
You can purchase A Whole New Normal, an acoustic neuroma journey on Amazon. The profits from the book will be donated equally to ANAC and ANA.

You can also contact me through my website:

www.awholenewnormal.com

or find me on Facebook at:

www.facebook.com/AWholeNewNormal



Invitation to Members

Inspire others and share your experience

We invite members to share their personal stories with other members. Your story should include how you were diagnosed, pre-during-post stages of your treatment/experience. The support you received from family and friends as well as lessons you have learned.

To submit your story, contact: Theresa Forson, National Coordinator.

Volunteer Acknowledgements

December 5, 2013 marked **International Volunteer Day**. In 1985, the United Nations established this special day to promote the tireless efforts of the many volunteers who contribute on local, national and international levels around the globe.

ANAC would like to thank the many national volunteers who contribute to the association. ANAC would not be where it is today without you!

Your skill, talent, support and efforts are appreciated by many, whose lives have been impacted by Acoustic Neuroma.

Volunteers are the only human beings on the face of the earth who reflect this nation's compassion, unselfish caring, patience, and just plain loving one another. ~Erma Bombeck

If you would like to be involved with ANAC in a volunteer capacity, please contact the National Coordinator for details.

Have You Recently Moved, Changed Your Phone Number Or Email?

Please keep us informed! ANAC regularly sends correspondence to you. If we can't find you, we can't keep you updated!

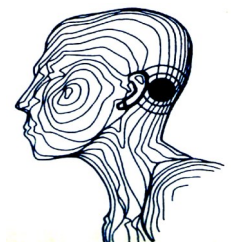
Help Us Spread The Word Together We Can Make A Difference

Are you a business or health care organization that would like to receive newsletters or other print material from ANAC?

ANAC has many printed materials available for your clients/patients such as pamphlets, bookmarks, business cards and a Acoustic Neuroma Resource Handbook. All materials have valuable information to support newly diagnosed Acoustic Neuroma patients.

Please contact Theresa Forson, National Coordinator to receive your copies today!

Caring
Sharing
Supporting



Thank You To Our Generous 2013 Financial Supporters

Judith Montgomery
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Evalyn Hrybko
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To Our Corporate Donors

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And to the many anonymous donors who designate payroll donations through employers and campaigns such as the:

**Ontario Power Generation
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United Way, Quinte and District**

In Memoriam of

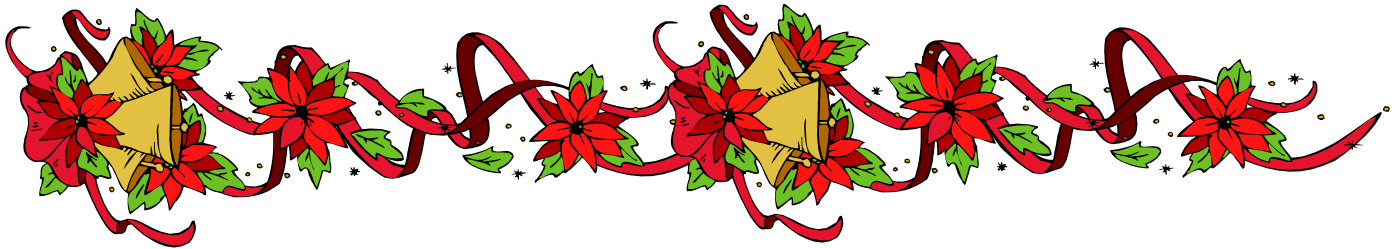
Palmira Lofft & Margaret Cawley



The world changes year to year
And friends from day to day
But never will the one we love
From memory pass away

Tis The Season To Give

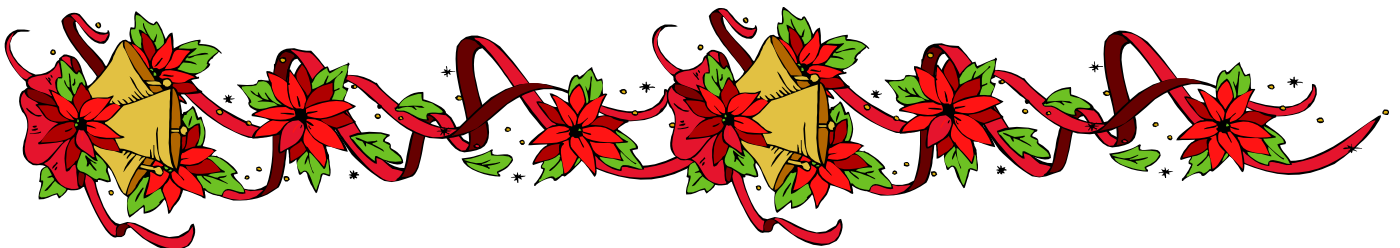
By: Jennifer Wong



As we approach the holiday season once again, charitable giving is a fantastic way that you can make a lasting difference for a cause you support. Starting in this year, The Canadian Revenue Agency introduced The First-Time Donor's Super Credit for individuals or families who have not made a charitable donation within the last 5 taxation years. This is an excellent incentive, by the Canadian Government, to give generously. Donors will be eligible for a 40% tax credit for the first \$200 amount and a 54% tax credit for every dollar over \$200 for up to \$1000 in credit. As if that wasn't encouraging enough, donors can receive their provincial tax credit in addition to the Super Credit. Altogether, cash donations made in the 2013 taxation year, are qualified for a whopping 61.1% tax credit in Ontario and a 74.4% tax credit in Quebec. For more information on The First-Time Donor's Super Credit visit the Canadian Revenue Agency's website <http://www.cra-arc.gc.ca/gncy/bdgt/2013/qa01-eng.html>.

Looking ahead, ANAC is still working to meet its \$25,000 goal for 2014. Donations (cash or cheque) can be mailed, faxed or emailed to ANAC, or securely submitted online through CanadaHelps.org and through the ANAC website www.anac.ca. It is a great time to give, knowing that ANAC is a patient-led organization mostly comprised of volunteers who work on Fundraising Committees, the Board of Directors, the Medical Advisory Board, Chapter meetings, website, newsletter and translation services. We try our hardest to make the most of your donations in agreement with our ANAC's policy, that all donations will be used to support the aims and objectives of the Association for the purpose of enhancing the support and information of patients and public on tumors affecting cranial nerves. We greatly appreciate your continued support as members, and belief in ANAC's mission of providing information about the treatment of acoustic neuromas, public awareness of the cause and promoting research for treatment. This holiday, give the gift that fosters ongoing involvement and awareness of acoustic neuroma across Canada.

For more information on how you can donate to ANAC, please contact the National Coordinator at 1-800-561-2622 or info@anac.ca



Facial Rehabilitation

Meet Jay Cooling, Physical Therapist, certified Facial Therapist



Jay graduated from Dalhousie University's School of Physiotherapy in the Maritimes – Halifax, Nova Scotia. Keen to gain a global understanding of the scope of his profession, he has since accrued experience across the continuum of care. His current approach and skill-set have been largely influenced by his time spent in a variety of care settings – from intensive and acute care to sports medicine, work conditioning, as well as long-term care.

In 2004, Jay developed a strong interest in working with individuals with complex medical histories, especially those who have been impacted neurologically. Fittingly, Jay has been working with the Community Accessible Rehabilitation (CAR) program in Calgary since that time. CAR is an active rehabilitation service supporting the needs of individuals, and their families, with chronic health conditions, acute exacerbations of medical conditions, and/or complex medical issues. Jay functions as a part of CAR's neurological interdisciplinary team, collaborating in the screening and development of individualized, goal-directed, treatment programs.

Earlier in 2013, Jay seized a tremendous opportunity to become one of four qualified Facial Neuromuscular Re-training (FNR) therapists who operate out of the CAR program. What began as 'peaked curiosity' has now turned into a passion. He is particularly interested in offering education and active treatment to those who have experienced facial palsy. This, most-often, includes those who have endured direct facial nerve damage, Bell's palsy, Ramsay-Hunt Syndrome, Guillain Barre Syndrome, and Acoustic Neuroma.

Having a facial palsy can have a significant impact on nearly every facet of an individual's life. Aside from altering external facial aesthetics and function, it often-times alters the way people think and feel about themselves internally. Fortunately, there is help available! With FNR, as well as an interdisciplinary team approach, good facial posture, function, and quality of life can be restored.

FNR is a highly rewarding and encouraging profession. It has consistently shown to be an effective means of optimizing facial function. As you might expect, the treatment of facial palsy will vary depending on the client's goals, as well as the timing, severity, and nature of their symptoms. There is no 'cookie-cutter' approach. As such, it is imperative to seek out a certified Facial Therapist prior to initiating treatment or applying uninformed, usually well-intentioned, advice.

During the initial phase of recovery, a certified Facial Therapist will thoroughly screen the client's facial function and begin the process of educating on the importance of diligent eye care, facial anatomy, the facial nerve (what it does and does not supply), time-frames for recovery, as well as expectations. As an adjunct to education, the client and therapist may begin to formulate a circulation and stretch routine to help improve symmetry, and to prepare the facial bed for future activity corresponding to the facial nerve's recovery and input. Also, it is important to identify any need for ophthalmological, dental, speech, and

Facial Rehabilitation continued

psychosocial support. These potential needs will all be considered at the time of assessment, and throughout the rehabilitation process. Once appropriate, the focus of therapy will advance to include fine, quality-focused, movement strategies to assist with eye closure, tone normalization, and facial function. Often-times, the Facial Therapist will use mirrors as teaching aids, as well as photographs and/or videos for documenting progress and providing feedback, as it can be difficult to observe changes on a day-to-day basis. The entire rehabilitation process can range anywhere from 6 to 36 months.

Throughout the process of facial re-training and recovery, it is important to see the Facial Therapist's role as being a coach. A coach can encourage, offer guidance, and give practice tips. Ninety percent of FNR will occur outside the rehabilitation clinic, in the home environment.

As such, the ultimate goal of a Facial Therapist is to equip the client to become their own, well-informed, 'therapist' over time. This is one of the greatest features of FNR. It literally places the tools in the hands of the client and in doing so, provides the client with the opportunity to build as high as their system will allow. This helps the client engage as an active participant, giving them a measure of control, not to mention a sense of accomplishment, over their ultimate outcome.

Just a couple of weeks back, one of Jay's young clients - who is still recovering from a facial palsy that began after Acoustic Neuroma surgery - thanked him for helping to restore her smile. She felt that she had finally gotten her life back. She wept in the treatment cubicle as he reviewed with her just how far she had come. In response to her heart-felt words, he reminded her how all he did was provide her with a chisel and a good reason to chip away. It was her that chose to take those tools and put them to use. Seeing her success, and its accompanying encouragement, is just one of the many reasons Jay loves what he gets to do for a living.

Jay is a member of the College of Physical Therapists of Alberta and is the Acoustic Neuroma Association of Canada's newest Facial therapist member.

In his free time, Jay thoroughly enjoys spending time with his wife, Janice, and 2 young girls. They enjoy running, hiking, swimming, and helping others together. After experiencing a dramatic life change in late 2004, Jay has devoted his life to helping people. More specifically, he is passionate about motivating the young and less-fortunate toward lives of purpose, significance, and value. Beyond spending hundreds of hours offering people hope, support, and food in the back alleys of Calgary's inner city, Jay has been asked to speak in a variety of contexts, throughout Alberta.

If you would like to schedule an appointment with Jay, he may be contacted through:

North - Community Accessible Rehabilitation (NCAR)

Rehabilitation Department, Peter Lougheed Centre, 3500 - 26 Avenue NE, Calgary, AB, T1Y 6J4

Department Phone: 403.943.4786 Direct Line: 403.943.4110 Fax: 403.943.4520

Email: jay.cooling@albertahealthservices.ca

Chapter Updates

The Kitchener/Waterloo Chapter Celebrates ANAC's 30th Anniversary

On September 14, 2013, we were blessed with a beautiful sunny day! Our hosts, Paul & Linda Darkes of the Kitchener/Waterloo Chapter, offered their home (and huge back yard) for our celebrations.



Fifteen adults and three children attended and we were delighted that ANAC's president, Dr. Carol-Anne Sullivan and her twins were able to join us for part of the event and three members of the Toronto Chapter also joined us. A 'get-to-know-you' bingo game helped us "Break the Ice" as we learned more about each other.

Members contributed a delicious assortment of appetizers and salads to compliment the burgers and sausages. To round off the meal a '30th Anniversary' cake was enjoyed by all.

The meal, enjoyed together, led to sharing our AN journeys and encouragement to realize that there is LIFE AFTER an ACOUSTIC NEUROMA!



Left to Right

Marilyn M., Allan J., Dona M., Tom H., Margaret S., Joan C., Gary C., Lorraine S., Ernie, Helen H., Carol-Anne S., Nathan, Nadia, Linda D., Kathryn H., Amy D., Linda S. Absent from photo: Doug S.

Chapter Updates

Manitoba Chapter

We had a great meeting on Saturday October 19, 2013. The new facility worked out famously, lots of room to stretch out, bright and open. The space will work well for future PowerPoint presentations. There is a huge screen and ample electrical plugs for the amplifier, as to make it accessible for everyone. Not to mention lots of parking.

There was fourteen of us in attendance and although the audiologist was unable to attend we were able to fill in the time by covering many subjects. The audiologist has been confirmed our next meeting. Our goal is to schedule presenters that represent improvements within our lives, be it for hearing, eyes or balance.

Thank you to the members in attendance for your participation, sharing your experiences and knowledge with us. Thank you Kelly for speaking about your personal experience with the CROC hearing aid , it was very informative. Thank you for our newest members Olga and Doreen for coming out to our meeting. Hopefully you learned a bit more about AN and our group, we are evolving as we go along. Thank you for those of you who brought snacks and thank you Faye and husband for the great coffee, snack and decorations provided.

For those who haven't heard, Luba has moved to BC, where I am sure she will be involved in the local Chapter. Faye and I would like to thank her for her contribution as a co-facilitator and for securing the lovely new space for us to hold our meetings.

I will be in touch periodically with Manitoba members, updating you on anything that may contribute positively to your lives and of coarse to remind you of the up coming Spring Meeting. Drop me a note anytime if you have any concerns, are in of need information or you know someone who may benefit from our group.

If you have means to advertise our Chapter, be it radio or written media please let me know. Help us reach others living with this condition by spreading the word about AN and the Manitoba Chapter.

The next Manitoba Chapter Meeting will be held on April 26, 2014 from 1:00 pm to 4:00 pm at the Transcona Access, 845 Regent Ave W. Room 165 (Same place as the Fall Meeting)



Take care, Annamaria

*Back row - Mike, Leslie, Terry, Doreen, Jackie, and Annamaria Palfly (co-coordinator), Roy Maguire
Front Row - Lynda, Faye Goranson (co-coordinator), Julie, and Kelly*

Chapter Updates

British Columbia Chapter

On Saturday October 19, 2013 the BC Chapter met at the White Spot in Courtenay. Eleven of us gathered for a time of sharing and visiting. Of the eleven, nine of us have/had Acoustic Neuroma. It is always wonderful to have AN supporters join our meetings. Although we didn't have any new people attend, it was good to be together and catch up on each others busy lives. One lady shared about her new hearing aide after many years of being deaf in the AN ear, and how pleased she is with it. It is similar to the CROS hearing aide.

We ended the meeting, noting that we were looking forward to getting together again next spring.

*Sincerely,
Evalyn Hrybko*

Ontario - Ottawa Chapter

On Wednesday September 18, 2013 the Ottawa Chapter held it's regular meeting at the Carlton Community Centre.

There were eleven people in attendance at the meeting that started fifteen minutes early (6:15) and lasted almost 2½ hours. It was probably our most successful support group meeting in past seven years.

I could not have been happier with the turnout, the mix of attendees and the lively discussions. There were three spouses, three (including myself) who were treated with the translab approach, one treated with LINAC, two treated with cyber knife, one scheduled for cyber knife treatment in October and one who is currently being monitored.

The Ottawa Chapter has started a Facebook group, please join us at ANAC OTTAWA/OUTAOUAIS.

*Best regards,
Nick*

Chapter Updates

Ontario - Toronto Chapter

ANAC'S 2014 TORONTO CHAPTER MEETINGS

Caring! Sharing! Supporting!

The Toronto Chapter meetings are held on the last Tuesday of every other month from 6:30 pm to 8:30 pm. We will meet in the Aural Rehab room on the 2nd floor or in the Boardroom on the 3rd floor as indicated below. Meetings are held at the Canadian Hearing Society (CHS) located at 271 Spadina Road.

Public transit - exit at the Dupont subway station. CHS is second building on east side of Spadina Rd. You can't miss the big sign in front of the building.

Please sign in at the Security desk on the main floor. Free underground parking is available.

2014 Schedule

Tuesday January 28 – 3rd FLOOR BOARDROOM

Tuesday March 25 – 2nd FLOOR AR ROOM

Tuesday May 27 – 2nd FLOOR AR ROOM - **10th ANNIVERSARY!**

Tuesday July 29 – 3rd FLOOR BOARDROOM

Tuesday September 30 – 3rd FLOOR BOARDROOM

Tuesday November 25 – 3rd FLOOR BOARDROOM

Please contact Chapter Leaders Lynda Nash or Kathryn Harrod if you have any questions.

Lynda Nash at 416-282-5918 or at lynda_lu123@sympatico.ca

Kathryn Harrod at 905-891-1624 or at tim.harrod@sympatico.ca

National - Virtual Chapter NEW!

ANAC is starting a new Virtual Chapter that will meet through Skype. The first meeting will be held on Saturday February 1, 2014 at 2:00 PM EST. If you are interested in joining us for an afternoon of Caring, Sharing and Supporting, please RSVP your attendance to the National Office at info@anac.ca or by telephone at 1-800-561-2622. Limited space is available.

Skype is a free online platform used for virtual meetings. Details and requirements can be found at: <http://www.skype.com/en/download-skype/skype-for-computer/>

If you would like assistance setting up an account or would like to conduct a trial run prior to the meeting, please contact the National Coordinator, she is happy to assist. If you are already a Skype user, please feel free to add us: **anac.2013**

Support Groups Across Canada

People who are diagnosed with an Acoustic Neuroma and their loved ones, often find help through an Acoustic Neuroma support group. Through support groups, people who have experienced Acoustic Neuroma, gather to share information, experiences and offer to support to one another. Within the safety of a support group, many people are able to share their past experiences, their fears and concerns about the future, and the day-to-day challenges they face. Support groups may also present speakers from the medical professional community to educate about Acoustic Neuromas.

Acoustic Neuroma support groups are located in various locations in Canada in the cities shown below.

For more information on meeting times and locations, please contact the individuals from the listing. Please contact the National Office at 1-800-561-2622 or info@anac.ca to speak with other patients in your region.

British Columbia: Courtenay / Nanaimo

For further information contact:
Evalyn Hrybko at 250-282-3269 or
email wehrybko@saywardvalley.net

Ontario: Ottawa

For further information contact:
Contact: Nick Dinelle 613-831-2426 or
email ndinelle@rogers.com or
Facebook: ANAC OTTAWA/OUTAOUAIS

Ontario: Kitchener / Waterloo

For further information contact:
Linda Darkes at 519-696-3445 or
email pdarkesc659@rogers.com
Helen Horlings at 519-954-5581 or
email healto@rogers.com

Manitoba: Winnipeg

For further information contact:
Faye Gorenson at 204-762-5611 or
email fsg@mts.net
Annamaria Palffy at 204-254-4409 or
email palffya@hotmail.com

Ontario: Toronto

For further information contact:
Lynda Nash at 416-282-0036 or
email lynda_lu123@sympatico.ca or
Kathryn Harrod at 905-891-1624 or
email tim.harrod@sympatico.ca

Ontario: London

For further information contact:
Margaret Dodgson at 519-451-3443 or
email dodgsonm@rogers.com or
Lorraine Swanson at 519-668-7737 or
email lor.anac@yahoo.ca

The Acoustic Neuroma Association of Canada is working to develop support groups in each province across Canada to ensure people affected by Acoustic Neuroma receive the support they need. Volunteers are currently needed in Alberta, British Columbia, Saskatchewan, Quebec and all East Coast Provinces. If you are be interested in helping establish a new group in an under serviced area, please contact Theresa Forson at the National Office for an information package and support.

info@anac.ca

1-800-561-2622

Caring Sharing Supporting!

Acoustic Neuroma is a benign brain tumour affecting the functions of the inner ear. It is often misdiagnosed or undetected. If any of the following symptoms persist, consult your physician.

- ***One-sided deafness, gradual or sudden***
- ***Balance problems or unsteady gait***
- ***Facial numbness, tingling, or spasms***
- ***Headaches***
- ***Dizziness***
- ***Visual disturbances***
- ***Tinnitus (ringing or buzzing in the ears)***



Acoustic Neuroma Association of Canada

Association pour les Neurinomes Acoustiques du Canada

The Acoustic Neuroma Association of Canada (ANAC) is a peer support group. Many who face and undergo removal of Acoustic Neuroma and other benign tumours involving the cranial nerves have questions, concerns, and physical and emotional adjustments. Membership in a group of those with similar experiences can be helpful to patients as well as family members and interested medical personnel.

As a registered non-profit organization, ANAC strives to:

1. Provide support and information to patients.
2. Furnish information on patient rehabilitation.
3. Promote and support medical research.
4. Educate the public to promote early diagnosis.

ANAC

P.O. Box 193

Buckhorn, ON K0L 1J0

T: 1-800-561-2622

T: 1-416-546-6426

F: 1-705-657-2365

E: info@anac.ca

Website: www.anac.ca

Newsletter prepared and edited by Theresa Forson. Please forward all comments, feedback and story ideas to info@anac.ca

Soigner Partager Soutenir !

Le neurinome acoustique est une tumeur bénigne dont la manifestation touche les fonctions de l'oreille interne. Il est souvent mal reconnu, ou non détecté. Si vous avez des symptômes persistants tel que les suivants, consulter votre médecin.

- **Surdité unilatérale, subite ou progressive**
- **Problèmes d'équilibre, de marche**
- **Perte de sensation du visage, fourmillement, spasmes**
- **Maux de tête**
- **Vertiges**
- **Troubles visuels**
- **Acouphène (tintement ou bourdonnement aux oreilles)**



Acoustic Neuroma Association of Canada

Association pour les Neurinomes Acoustiques du Canada

L'Association pour les neurinomes acoustiques du Canada est un groupe de soutien. Les personnes confrontées au neurinome acoustique et à son ablation ont souvent des questions ou des craintes face à leur situation, mais aussi des besoins de réadaptation physique et émotionnelle. Notre mission d'organisme à but non-lucratif est de :

1. Soutenir et informer les personnes diagnostiquées du neurinome acoustique
2. Rendre disponible l'information sur la réadaptation des patients
3. Promouvoir et soutenir la recherche médicale.
4. Éduquer le public afin de promouvoir le diagnostic

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Bulletin préparé et édité par Theresa Forson. Merci de communiquer tout commentaire et proposition à info@anac.ca