



Manitoba Lung Cancer Voice

Fall 2021

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November is Lung Cancer Awareness Month

www.lungcancercanada.ca

November is Radon Action Month

takeactiononradon.ca/radon-action-month

Reflection

The Manitoba Lung Cancer Support Group (MLCSG) was founded in April 2019 by Alyson and myself. Since then, lung cancer patients and caregivers have had monthly meetings to share information and encourage and inspire. We also invite doctors, nurse practitioners, and therapists to talk about all kinds of lung cancer issues, such as the basics of lung cancer, targeted therapy, immunotherapy, palliative care, mental health, etc., all happened in Manitoba. The monthly meeting is on the fourth Tuesday of each month from 10:30 to 12:00. See pictures below.

Recently, we started a quarterly newsletter, "Manitoba Lung Cancer Voice" as you will see here. The newsletters reach Manitoban lung cancer patients who want to connect with other Manitoban lung cancer patients. Additionally, we are interested in connecting with early-stage lung cancer patients.

The current members of WLCSG are the primary sources of information and authors of articles for the newsletters. Thanks to Mr. Michael Edwards, who is our chief editor and always there to support WLCSG. Also, thanks to CancerCare Manitoba for facilitating this effort. If you have any questions or want to contribute to the newsletters, please contact Michael at medwards6@cancercare.mb.ca



Christine Wu

Would you mind sharing your opinion on the following two questions? Your identity will not be published in the newsletter, unless you give permission

What long term effects of lung cancer do you feel?

What are the tips on how to prevent caregiver fatigue?

Send your answer to Christine.Qiong.Wu@outlook.com

News Release:

It was announced that the new Genome Sequencing Laboratory opens at CancerCare Manitoba. "Precision medicine is the new generation of cancer therapy. The new Genome Sequencing Laboratory will allow CancerCare Manitoba and Shared Health to use precision medicine to conduct genetic testing in Manitoba, which brings new treatment options and faster turnaround time for results," said Dr. Sri Navaratnam, President and CEO of CancerCare Manitoba. The Genome Sequencing Laboratory is capable of testing more than 30 genes simultaneously in multiple tumour types.



https://www.cancercare.mb.ca/About-Us/communications-and-public-affairs/news-archive/News-Release-New-Genome-Sequencing-Laboratory-Opens-at-CancerCare-Manitoba?fbclid=IwAR1oyX-4tkFnkMZda-MFTL6OJXq7VDyKwA_oJidIggHQjRKIW-j31Z6Dic4

(This is from CCMB Communications and Public Affairs. Permission might be needed.)

Photo featuring (LtR) Dr. Sri Navaratnam, President and CEO of CancerCare Manitoba; Dr. Amin Kabani, Medical Lead, Provincial Laboratory Diagnostic Services, Shared Health; and Annitta Stenning, President and CEO of CancerCare Manitoba Foundation.

Lung Cancer Canada's Lung Cancer Awareness Month Events

For more information and to register, visit: <https://www.lungcancerCanada.ca/Get-involved/LCAM.aspx>.

All the events require registration, but are free to attend!

Friday November 12:

Stakeholder Briefing 1:00 pm - 3:00 pm EST

Join us for the launch of the 2021 Faces of Lung Cancer Report, discussion of impacts from COVID-19, treatment updates and interesting breakout sessions!

Thursday November 18:

National Virtual Patient Summit 6:00 pm - 8:00 pm EST

Get informed and build your community at this patient and caregiver focused event! Topics include New treatments, COVID-19, Clinical Trials, Exercise and more!

Wednesday December 1:

Webinar Series: What's New in: Radiotherapy 12:00 pm - 1:00 pm EST

The next installment of our What's New series - with Panelists Dr Corinne Finn and Dr David Palma

Sunday December 5:

Evening of Hope 6:00 pm - 8:00 pm EST

A national, & virtual event celebrating survivorship and the progress being made in the fight against lung cancer

News & Events

Manitoba

Lung Cancer Support Group, Facilitated by Psychosocial Oncology Clinician Mike Edwards; Occurs the 4th Tuesday of every month, 10:30-12:00, no registration required; During COVID meetings take place over ZOOM, please email Mike if you wish to attend (medwards6@cancarecare.mb.ca), or enter ZOOM Meeting ID: 819 0992 0588
Passcode: 647705

Don Barrett's Story

Hello, My name is Don Barrett and I was Diagnosed with Stage 4 non small cell carcinoma, EGFR T 790 M with metastasis to the lining of my heart, bone and kidney. I am here today to share with you a bit about my journey and my experience with cancer. I would like to begin by stating that my experience with CancerCare Manitoba has been remarkable. The nurses, doctors and support staff are amazing.

My story began In September 2017 when I suddenly had difficulty breathing at home. I was rushed to the hospital by ambulance and it was then I was advised my lungs were full of blood clots. The doctors were very surprised by this and therefore further investigations were completed which identified a small spot on my kidney however they were unsure of its significance and were not concerned with it at that time.

January 2018 I again began to develop difficulty breathing with profound fatigue in the days preceding. I collapsed at the hospital doors when walking to a doctor's appointment. I was again rushed to HSC emergency where an ultrasound showed a significant amount of fluid compressing on my heart called a "cardiac tamponade." I was told then that if there was 1 oz more of fluid I would have been dead. I was quite sick at this time and they did not think I was going to make it through the night and my family was called in. Luckily I didn't pass at this time. I was admitted into the hospital for 2 weeks where they continued to remove this fluid from my lungs and from the area surrounding my heart. At this time the doctors remained baffled. They had their suspicions I had cancer but were unsure what the primary source was.

In February 2018 I was finally given the diagnosis of stage 4 cancer with an estimated 6 months to 1 year to live. I was placed on the palliative program and began to get my affairs in order. I was to begin chemotherapy, but shortly after was advised that chemotherapy would not be of much benefit for my cancer and therefore was started on Gefitinib which is a specific cancer medication which attacks the mutation of the type of cancer which I have. Things were looking up for me. My fatigue remained unchanged however I was able to return to my life at home.

June 2018, I had another episode of fluid collecting around my heart and in my lungs and was admitted to St. Boniface Hospital. Upon arrival I had 1800 ml of fluid removed. Again the doctors were amazed that I was able to tolerate such a large amount of fluid on my heart without more symptoms of just my fatigue.

Since this time I continue to have CT every 3 months, while also having bone scans and MRIs from time to time. I have received radiation for the bone cancer found in my scalp which was causing me pain which really worked in curing my pain to this site. My medication was also changed from Gifitnib to Osimertnib as a result of my cancer continuing to mutate and the newer drug working more effectively against the newest mutation.

My message to you is this. Yes, what I have gone through may sound extensive and exhausting. But you get the cards you are dealt and the best thing we can all do is keep our positivity, get our affairs in order, and then enjoy the rest of the time we have on this earth.

I am very fortunate to have family, grandchildren, friends and other supports. I was advised in February 2018 I would likely only have 6 months to live and I am still here. I do more today then I was able to do a year ago and I attribute much of that to my continued positivity, the wonderful people in my life and the staff at CancerCare Manitoba.





SCANXIETY by Jan Fontaine

Firstly, a bit of background. I was diagnosed with small cell lung cancer (SCLC) in December 2018. After undergoing several tests – CT scan, MRI, bronchoscopy, and PET scans, a tumour was found in my left upper lung. Its location near my heart meant surgery was not an option and thus began several rounds of chemotherapy and radiation. Initial results were effective and subsequent scans showed that the tumour had indeed shrunk, which is quite common as SCLC is quite receptive to treatment initially. However, what is also quite common is that the tumour will reoccur or increase in size over time. After a year, my tumour showed new growth and more chemotherapy was ordered. Again, that proved successful. And so, here I am today.

My latest scan (August 2021) was stable in appearance and showed nothing of interest – just scarring from prior radiation treatment. Good news tempered as always by the reality of SCLC. Thus begins another three-month interval between scans. The anxiety is put aside until the next time.

SCANXIETY – a combination of two words – scan and anxiety - is a term most, if not all, cancer patients are familiar with. For those few who may not know that word – but surely have experienced the feeling – it is the term commonly used to describe the stress that is felt in the days leading up to and in the days following a diagnostic test, be it an MRI, PET or CT scan. Cancer patients are all too familiar with these scans - used to diagnose and establish, in conjunction with other diagnostic tests, the varying types and stages of cancer. Then during and after treatment, they are used to ascertain the efficacy of treatment received.

Wherever you are on your cancer journey, the spectre of scans is ever present. The more stable or unchanged your scans are from one to the next, the longer the interval between scans. I would like to say that scanxiety eases over time but in my experience and from stories I have read from other cancer patients, it never really leaves you, though the further away you are from your initial diagnosis or any recent changes, the less scanxiety you may experience. It becomes just a part of your cancer journey.

So, how do you handle the inevitable anxiety and worry that usually takes hold in the days prior to the scan until the results are known? This holding pattern, if you will. I find it hard at times to hold negative thoughts at bay. All the 'what ifs'. You know that no amount of worry will change the result but turning these thoughts off isn't easy. If you are fortunate, the wait time between scan and results is a short one though sometimes it takes several long and seemingly interminable days to finally get the answer you are both dreading and hoping for. Waiting is the worst part. Hopefully the news will be positive and life carries on until the next scheduled scan and so it goes for as long as the cancer exists. A recurrence would, of course, necessitate further treatment and all that entails.

There are as many ways to cope with scanxiety as there are survivors. Some become overwhelmed with fear and dread, asking friends, family and other cancer survivors for prayers and positive reinforcement. Others may try to keep as busy as possible with work, advocacy or hobbies – anything to keep their thoughts and worries at bay. Some others choose to put aside all thoughts of results and simply await the oncologist's call to hear the news they sometimes dread but always hope for. No amount of worry will change the inevitable result though in saying that, it doesn't make the waiting any easier to endure.

Everyone must find what works best for them. I have a personal mantra that I recite whenever I feel the stress building and that seems to centre me and bring me a measure of relief and peace. I hope to reach a point where the scans are ever further apart and the scanxiety eases, though I fear it will never leave me completely. I put all thoughts of cancer aside as much as possible during scan intervals. Such is the nature of an incurable disease.

My motto since diagnosis is "It is what it is" and "What will be, will be." I choose to live with hope and to walk with faith - one day at a time.

The Day and Diagnosis That Changed Our Lives Forever

By April Hildebrand

Life is full of obstacles, good times and bad, though some of those events are forever imprinted in hearts and minds. At the beginning of April 2018 my dad's shortness of breath was getting worse and he had begun coughing up some blood. He went to the emergency room where they did a chest x-ray. We were worried, but the chest x-ray showed no evidence of cancer and thus we were relieved. The x-ray appeared normal but the Doctor ordered a CT scan to be sure. My father received a call from the Doctor and was told there was a 1.58 cm nodule in his upper left lung. After many tests and a biopsy done in June, my father was given the diagnosis of lung cancer. Nothing can ever prepare you for that sort of diagnosis and the cancer journey can never really be understood until you or one of your very close loved ones is faced with going through it. It felt like my father was handed a death sentence and there was no hope. I sat in my car and cried when I found out. It was a day that I will never forget and there would be many hard days to follow as I tried to support my dad through his lung cancer journey.



As a caregiver, I can't begin to imagine how it feels or speak to being the patient. I can only share my perspective and some of the feelings my father has shared with me. This lung cancer diagnosis and the path to follow was an overwhelming experience filled with a roller coaster of information and emotions for my entire family. Initially, my father was told his cancer was Stage 1. He could be cured with surgery or a special radiation therapy. After much deliberation, my father decided radiation would be more appropriate for him than surgery. It was a scary and exciting time. Exciting because we were given hope that maybe my dad's lung cancer could be cured. The treatments were exhausting for my father with daily three-hour trips to Winnipeg for two weeks straight. He experienced minimal side effects throughout and was so ecstatic to be able to ring the bell when the radiation treatments were finally done. Unfortunately, we were only able to celebrate that victory for a few months and were then told that the radiation did not work and that there were more new spots showing on the scans. At this point, my father was referred to Oncology and we were all devastated.

The Oncologist was full of hope and started talking about cure. My father and our family were so confused as we were just told there was no hope. My father was so brave and wanted to fight for his life and more time with his family. A second biopsy revealed NSCLC Adenocarcinoma with no targetable mutations. In December 2019 he started thirty daily radiation treatments along with six weekly Carboplatin/Paclitaxel treatments. These treatments were unsuccessful and we had to consider next options for his care. In April 2020 he had four rounds of Carboplatin/Pemetrexed/Pembrolizumab. These treatments were very hard on my dad. He experienced severe fatigue, loss of appetite, dizziness and suffered from depression and anxiety. He was not able to enjoy time out of the house or with family. The anxiety of what the next scan would show was debilitating and his quality of life was depressing. This had become a chronic, stressful fight to stay alive and it felt like a losing battle. My father endured the treatments, but again we were met with the heart-breaking disappointment that the treatments were not successful. Being slammed with the devastating news again of no hope. To receive that news over and over again that there is no hope and nothing further than can be done is unspeakable misery.

My father and our family were not ready to give up this fight against lung cancer. We were able to receive amazing support, information, and encouragement for advocacy from the Winnipeg Lung Cancer Support Group and the Facebook group, Canadian Lung Cancer Advocacy. The people in these groups have been a

tremendous gift to my father and our family. They have a wealth of information and are so inspiring. With encouragement and support from these strong advocates and with the help of CancerCare, my dad was able to be part of a clinical trial. This opportunity gave my father and our family that little glimmer of hope we needed to keep on going. The trial medications Lenvatinib/Pembrolizumab were started in November 2020.

My father did well on the clinical trial and it controlled his cancer until July 2021. Now we are again on the path of deciding what's next and hoping for another clinical trial to magically appear. One of the hardest parts of this journey is trying to understand why clinical trials are not more readily available in Manitoba and learning how to advocate for that. Also, trying to understand why a certain medication can't be tried if a person is faced with death anyway. Being told that there is nothing that can be done and death is certain within a few months is very hard to accept when there are medications available in other provinces and countries that could help. The red tape and logistics of fighting cancer is very disheartening.

Our family is small and close knit consisting of my father, mother, sister, myself and my husband and daughter. My dad's fight against lung cancer has brought us even closer together. My father is not one to speak much to his emotions, but lung cancer has forced him to. We have had hard discussions and shared our feelings so much more in the last two years. It is very hard to cope with the thought of losing him, but we are trying to enjoy every moment with him. For my father it has been hard to enjoy life as learning to live with cancer is very difficult. My father has developed close relationships with his nurses and doctors and has appreciated all of their hard work. One of our favorite past times together is fishing trips and other travelling. My dad was able to come fishing in Grand Rapids this past June and we took a family trip to Canmore in the summer of 2019. We had hoped to get to Nova Scotia in the summer of 2020, but COVID made that impossible. My father's lung cancer diagnosis has brought my sister and I into advocating for more money to lung cancer research. It has enabled us to find support and understanding in those with similar experiences. Though we are unable to attend monthly meetings, just knowing that the Winnipeg Lung Cancer Support Group exists is a huge comfort.

Lung cancer research has suffered due to the stigma and association between lung cancer and smoking. It is so wonderful to see the lung cancer advocates fighting to end the stigma attached to lung cancer and raising awareness. If you have lungs, you can get lung cancer. If you smoked prior to getting lung cancer, testing options and treatment options should be the same as if you didn't. Shame and blame should not be placed on anyone with cancer. Cancer can happen to anyone and is not solely based on risk factors controlled by the individual. My hope for the future is that clinical trials will become more readily available and that lung cancer research will receive more funding. I hope that anyone newly diagnosed with lung cancer will take advantage of the amazing lung cancer support group that Winnipeg CancerCare has to offer.





What is ALK + Lung Cancer? By Alyson Haiart

There is not just one type of lung cancer. Non-Small Cell Lung Cancer, Adenocarcinoma can be further divided into those that have identifiable cancer drivers. Anaplastic Lymphoma Kinase (ALK) is one of these, accounting for 5% of cases.

Everyone is born with the ALK gene which helps the embryonic development of the digestive and nervous systems among others. When the ALK rearranges itself ALK + lung cancer develops. There is no known reason for this to happen and I've been assured by my oncologist that this rearrangement is not hereditary.

With the identification of ALK targeted oral therapies have been developed. These treatments will not cure the cancer but put it "on hold" until the cancer finds a different path to take. At this point the cancer progresses. Ongoing research continue to develop the next generation of targeted therapies.

Story Like You Mean It. For Advocacy and Fundraising.

This was a joint presentation by Dr. Rebello, professor, motivational speaker, and author along with Chris Draft who is a lung cancer advocate and ex NFL player. Dr. Rebello's presentation was based on his book "Story Like You Mean It" so that you can tell your ALK+ story your way.

It was stressed by Chris that telling your own story is powerful and creates space and allows for others to tell their story.

Major themes to help story to be written are:

Self Hero (past life)

Collaborative Work (the present)

Your Virtuous Self (the just now and the future)

Within these headings you can identify positive lived experiences. Past formative moments usually occur in your teenage years, for example discovering self-reliance. Collaborative moments show how you are with others and have lived life as a social being. Illustrate by intentional decisions to join and work in groups.

Telling your Story is part of your Virtuous Self and provides a way to relate to others. Dr. Rebello also stated that obstacles are part of life and add to your lived experience. Identifying and learning about your skills can help you find meaning in your life and will help to give you the energy to voice your story.

It was articulated by Chris that to own your story one must accept the fact that you have lung cancer. He described how his wife, who died of lung cancer, never voiced a "Why Me", and accepted that non-smokers can also get lung cancer. He went on to stress that having lung cancer is not your fault. It is important to know that cancer is only a part of a person's story. That for advocacy it is important to know yourself, understand your community and where you fit. Also remembering that cancer doesn't take away your past life, which is what makes your story special and unique. By telling your story you can inspire others and that each person's story will survive them. You will feel proud and energized and in turn you will energize others, in this way we are stronger together, this can be transformative for others.

Dr. Rebello ended by saying practice your story, use your smart phone to record it, share your story with someone that can give you real advice, and these will give you confidence when presenting.

The book goes into depth explaining Dr. Rebello's method and has many useful exercises and diagrams to assist you in creating your powerful story.

Resources for Patients and Families living with lung cancer:

CancerCare Manitoba Patient and Family Resource Center:

Rm ON1016—675 McDermot Ave
Kathleen Helgason 204-787-4367

Psychosocial Oncology Department:

204-787-2109

Psychosocial Oncology Clinician (Counsellor/Social Worker):

Mike Edwards 204-787-1325

CCMB Patient Representative (Patient advocacy):

Heather Purvis 204-787-2065

CancerCare Nutrition Services:

204-787-2109

Lung Cancer Canada:

<https://www.lungcancercanada.ca/>

CancerChat Canada (Canadian Online Support Groups):

<https://cancerchat.desouzainstitute.com/>

Facebook:

Canadian Lung Cancer Advocacy - Breathe Hope
https://m.facebook.com/groups/520424908293279/?ref=group_browse

Palliative Care Program Info Phone Line:

204-237-2400

Omelet Muffins



PREP TIME: 5 MIN

COOK TIME: 20 MIN

TOTAL TIME: 25 MIN

SERVINGS: 12 muffins

Ingredients

- 12 large eggs
- 1 cup cottage cheese, drained
- 3/4 cup shredded cheddar cheese
- 1/4 cup chopped green onion
- 1/4 cup chopped peppers (optional)
- 1/4 cup chopped bacon, ham or sausage (optional)
- 3/4 teaspoon each, salt and pepper

Instructions

1. Preheat oven to 350°F | 180°C. Grease paper-lined 12-cup muffin tin or silicone muffin cups.
2. In large bowl, whisk the eggs. Add remaining ingredients.
3. Divide the mixture between 12 muffin cups
4. Bake for 20-25 minutes until puffed up, brown and cooked through.

NOTE: To freeze, cool completely and place in a Ziploc bag or plastic container. To thaw, place in fridge overnight. You can also reheat 30-45 seconds in the microwave from frozen.

Adapted from www.slenderkitchen.com