



***A PATIENT-FOCUSED ORGANIZATION***

## **VIRTUAL NATIONAL SUPPORT GROUP MEETING VIA ZOOM**

**SUNDAY, JANUARY 16, 2022**

### **EXECUTIVE MINUTES**

#### **Life is life, fight for it**

**Note:** The purpose of these minutes is to share information among members of the group and to provide a journal of various treatment journeys. While names are not used to protect privacy, it is never possible to completely guarantee anonymity or confidentiality. If you do not wish to have your (anonymous) information included in the minutes, please inform the chair. If you share personal health information about anyone other than yourself (at the meetings or otherwise), we assume you do so with his or her permission.

#### **1. Research**

Click here to see this month's treatment & clinical research updates: [Treatment and Clinical Research Updates](#).

##### **Research Article #27: Foods for Fight Colorectal Cancer**

Turmeric, Spinach, fruits, nuts, whole grains, legumes, and fish decrease your risk of developing colorectal cancer. Processed foods such as bacon, red meat, and alcohol increase your risk.

CCRAN's "My Foods for Life" Program, which was developed with the assistance of the American Institute for Cancer Research, is a primary and secondary cancer prevention program, and more. This program is particularly helpful for patients undergoing adjuvant chemotherapy and then looking for recommendations on how to lead a healthy lifestyle to help avoid a recurrence. It's also very helpful for any Canadian wishing to avoid colorectal cancer diagnosis in the first place.

You can find tasty and easy to prepare recipes you can follow to help follow a healthy diet.

My Foods for Life Booklet can be downloaded and printed from the CCRAN website. We can provide you with a hard copy if you wish via mail. You'll find tips to help address treatment induced side effects while actively undergoing therapy. Please access your copy at: <https://ccran.org/programs-advocacy/>

My Foods for Life is based on the World Cancer Research Fund recommendations which is a world-renowned authority on cancer prevention.

Supplements high in antioxidants are to be avoided during active treatment as they may negate or counteract the effects of chemotherapy or radiation. Vitamin B 12 and Turmeric are examples. CBD oil hasn't been adequately studied, but generally you should avoid antioxidants during the days you're being infused. There is ongoing research on Vitamin D, and they are reporting great results in increasing efficacy in tumour regression in the metastatic population. It is recommended that nutrition is best achieved through whole foods, rather than supplements if at all possible.

## 2. [Sharing](#)

(Please note: Not all patient and caregiver stories are contained in this document. Please join us at our Zoom meetings every third Sunday of the month to gain the true benefit of patients' inspirational journeys. See upcoming meeting dates appearing at the end of this document). Comments have been edited for clarity.

**[New Case #285]:** She had abdominal discomfort July of last year (2021). They thought it was constipation and tried a couple of medications for that. Ultrasound followed next which detected her disease. She had chemotherapy and did 9/12 treatments FOLFOX with panitumumab. There is no option for now of surgery. The CT showed a decrease in lesions and lumps (50-70%). The tumour was a left sided primary in the rectum. She had genomic profiling of the primary tumour through Foundation One. She is currently waiting for the results. She has liver metastases and a spinal metastasis on L4. She had backache and went for radiation before chemotherapy. She is feeling a lot better. CCRAN members were very supportive, and patients found the story very hopeful.

**[New Case #286]:** Her colorectal cancer was identified during colonoscopy in the sigmoid, and the blockage was identified as cancerous via biopsy. An 8cm section was removed adjacent to the rectum. 29 lymph nodes were removed and no disease was found in them. She developed some complications due to scar tissue while she was healing from surgery. They identified 6 nodules on CT in the lung. She was unable to secure good care in Asia, and she suspects that pollution may have been a factor. A lung resection surgery was done for biopsy in the right lower lobe of the lung. She had 4 nodules in the right lung and 2 in the left lung. The oncologist was not in favour of further resections. She and her husband lived in China and Indonesia and pollution levels were high, so they thought it may be a primary lung cancer but lung pathology confirmed metastatic colon cancer. She had 6 treatments of targeted chemotherapy (FOLFIRI plus bevacizumab). The lesions were stable afterwards or slightly decreased in size. There were no new lung metastases. She felt her specialist didn't like being questioned. Her tumour is MSS Stable and has an NRAS mutation, immunotherapy is not recommended. Since she has limited lung disease, she may be able to consider SBRT. She would need to be off systemic therapy for a period of time. It is intense, highly targeted radiation therapy that can blast the nodules. Surgical therapies may be revisited afterwards. Another consult with an oncologist can be facilitated with the family doctor. They don't currently have a family doctor due to shortage but have been assigned a nurse practitioner but a walk-in clinic can do this also. They drive 2 hours to see their oncologist. CCRAN has consulted with the medical oncologist and has determined the following: there are multiple nodules in the lungs which are quite small and are being optimally treated with systemic therapy. The patient is responding quite well to the therapy. There is low volume disease in the lungs and should continue to respond well to the systemic therapy. No other disease has been identified outside of the lungs.

**[New Case #287]:** He is a stage 4 colorectal cancer patient, who was recently presented with a grave diagnosis with only a few months to live without chemotherapy (6 months without chemo, 2 to 4 years with it). His primary tumour was a rectal tumour (left sided). He feels fine and has no symptoms. He has been off chemotherapy. He was offered a biopsy of his metastases and genetic testing and is on the waiting list for POG (Precision Oncology Group) program in BC. You must be off chemo to qualify for this program testing. The hope is that it may discover information which can lead to a promising clinical trial. His adjuvant chemo did not shrink his lesions. The first time on adjuvant chemo, he had an allergic reaction and wound up on 75% of his dose. He is a dentist and feels that surgery would be the definitive answer for him.

**[Case #197]:** His original diagnosis (stage III rectal cancer) was in 2008 and he was in remission for 10 years. He got a diagnosis of stage 4 in 2018. It took him 3.5 years to find a lung surgeon with the help of CCRAN. He had chemotherapy for 3 years and then in 2021 he had lung surgery, in both of his lungs, one at a time approximately a month apart. His first lung surgery (right lung) was in September of 2021. He recovered and had the left lung done Nov 16. Both were very successful. The surgeon removed all the cancer he could see. Had a significant burden of disease removed via surgery. It took 3 years of chemo to get them shrunk enough to the point where they could become resectable. They will attempt chemotherapy again now because of the disease he has in his peritoneum. They will attempt more targeted therapy with chemotherapy. He had radiation therapy on his pelvis over the Christmas holidays and now the pain is gone. He's feeling very fortunate there. He had COVID (Delta variant) which made him very sick (much sicker than cancer treatments). He will be starting second line therapy and continue to chip away at the disease.

**[Case #288]:** She's a caregiver to her husband. He has stage 4 with 3 nodules in lungs, 2 on one side and one on the other and a peritoneal nodule. He's been on FOLFIRI and Avastin (standard of care). It's been good for him. The abdominal tumour in particular was shrunk by 50%. He had ascites, which resolved with chemotherapy. In September he was still doing well. He had a severe reaction to his first chemotherapy treatment. His subsequent ones were much better. They went on a trip in BC on a vacation period and also visited New Brunswick. It gives you something to look forward to when you have a vacation as a cancer patient. He started a new treatment in Toronto. He is having a locoregional hyperthermia treatment to the chest and abdomen through the Marsden Clinic (Dr. Eric Marsden runs the clinic and is on CCRAN's medical advisory board). The CT is postponed due to the hyperthermia treatment, as the hyperthermia is stopped before scans. One nodule on the lungs was 6mm but it is now 12mm. The other nodules are stable. The peritoneal nodule has slightly decreased. He has a consult with a radiologist who recommended that he start stereotactic radiation therapy. The radiologist recommended 3 treatments of 45 minutes and feels very hopeful that it will be helpful. She may consider in vivo lung perfusion in future. More options for genetic testing are available through OncoHelix. She is grateful to CCRAN and our staff's hard work.

**[Case #253]:** Her husband was diagnosed at stage 4 last summer (2021). His primary is in the right colon, metastasized to liver in 6 spots. He responded well as far as side effects from chemotherapy. In December, they found out he wasn't responding to the hepatic arterial infusion pump (HAIP) chemotherapy Program and couldn't remain in the program. He is out of the clinical trial. First line treatment and the HAIP program were not working and they have to find other treatment options. The disease is confined to the liver. Living donor transplant program is being considered but not likely a candidate. Her husband's sister would be willing to do a transplant if it was possible. The metastases are in 5 different sections. The tumour pressing on the bile duct caused jaundice. There was only 3 days between finding out about the progression and development of jaundice. The second line of treatment is FOLFOX and Y90, possibly at Sunnybrook.

**[Case #213]:** She was unable to stay to present her update at the last meeting, there was some suspicion of liver metastases at the so CCRAN got in touch with an oncologist and she met with him. He felt the scans were not calibrated properly. She had to have a scan done at Princess Margaret in November. She had another allergic reaction during the MRI with the injection. She was given a pre-protocol and they had to stop halfway through. She missed her scan in December because of the reaction she suffered. She's unsure what to do at this point, as she doesn't want to go through the reaction again. CCRAN would be happy to assist with the appointment with her surgical oncologist to resolve and explore the reaction she suffered. She has a permanent ostomy and is interested in information regarding diet for ostomy patients. She finds that dietitians and nutritionists sometimes don't have very specific information.

**[Case#208]:** She doesn't remember the last 3 months of her life. She's been lying in bed flat with vertigo, brain metastasis, and thyroid storm. She was in a fog. It was explained to her that the vertigo is due to the thyroid problem. They removed the steroids, and she became paralyzed from the neck down on one side of her body. She was unable to shower or urinate and had some emotional difficulties. They removed the thyroid and she felt so much better. The thyroid was full of colorectal cancer, the problem was with the voice box and were concerned she may be mute. The laryngeal nerve was also riddled with cancer. There were nearby lymph nodes riddled with cancer too. They were surprised with the extent of the disease. Her voice is a little lower now, but she can still speak. They had to shave the nerve to get rid of the disease. Lucy now has very little disease in her lungs. The brain metastasis has been radiated. They're not sure where things are with the necrotic tissue with the brain surgery. There are also a few cancer cells left behind after shaving the laryngeal nerve. Two years ago, the MRI showed nothing, and in two and a half years she developed a 2.5cm brain tumour. Brain metastases are rare. She's been an amazing survivor. She's very excited about Moderna and their work on mRNA vaccines. The steroids are kicking in and she's almost able to walk again. Her next scan is in January. She's going to get a port and get chemo with Avastin after the scans through the winter.

**[Case #261]:** She has stage 4 colorectal cancer. She has innumerable metastases to lungs and one lesion on the liver. She did 10 rounds chemotherapy in 2020. She was approved for surgery. The one lesion left on the liver is 7mm. The CT scan showed only 1 nodule left in the lung. She had her entire colon removed and she has a permanent ileostomy now. During a break from chemo, the lung and liver metastases grew. She restarted CAPIRI in January of 2021. She did 9 more rounds. They were all stable except 1 liver spot. She was going to do RFA, but during prep, the radiologist found ascites and found metastasis in her ovary of 16 cm. Her stomach was so distended she looked pregnant. Things spiraled out of control this last summer. The following week she had sepsis and was admitted to hospital for 3 weeks. Second line treatment via chemotherapy was recommended. She had her ovaries removed this October and is happy to go through menopause in her 30s due to reduced risk from her metastases. She started capecitabine in December. Her blood work wasn't great before Christmas and she started CAPOX. The side effects were awful. She should have had treatment again this week but her son had COVID, so she will go tomorrow. Finding tests have been difficult for COVID. They were unable to run a full genetic panel but have found out that she is Her2 positive. Now that they have a 22cm ovarian tumour she wonders if she could have more testing done. Feeling really good aside from the awful effects from Oxaliplatin. Had a lot of success with CAPIRI.

**[Case#227]:** The masses in her liver had shrunk. She only had 5 infusions of immunotherapy, but it was a great success. The last one was in May 2020. Since then, all CT scans have been great. Recently, she had a nodule appear on her cheek, and had the tumour removed surgically. She was supposed to have an ileostomy reversal but it's been rescheduled and hopefully in the next couple of months. She would prefer not to have a surgery in the summer, but part of her just wants to get it done. The group

recommends that she get it done as soon as she can get a date due to current environment with COVID-19.

**[Case #239]:** She was diagnosed in 2010. The team thought it was curable, but it turns out it was stage 4 all along. She had a delay in colonoscopy due to her doctor thinking that colon cancer doesn't happen in patients under 50. It grew into the tissues and pelvic side wall, so it's permanently inoperable. She is on her 12<sup>th</sup> year of stage 4 disease. She was on panitumumab, irinotecan and 5FU, in the summer, had a low CEA, and scans had been stable. She went on a 3-month break, which was extended to 6 months due to COVID related booking problems. She had a PET scan in November, and it showed progression. CEA went up a little, and it's a good marker for her. In November, she wanted to restart right away, since this is the 4<sup>th</sup> time it's happened. Doctors could only book for January. Too few nurses resulted in surgical delays. She needed a stoma revision since she has a permanent colostomy. Since she needed to be off chemotherapy for the minor procedure off chemotherapy and had to wait for weeks afterwards. She was able to start again this past Tuesday. Her CEA has gone from 4 to 7 and she could feel pain rather than pressure in the right pelvis.

**[Case#164]:** She has a permanent colostomy and is worried about irrigation. Others say it's not very much of a hassle and takes about 20 minutes. Our patients found this reassuring. Colon Town was recommended by other patients for irrigation techniques. It doesn't work well for an ileostomy. It may not be the same experience for everyone, so care is merited. You may need to take your time. She's a survivor and she's doing very well. She was diagnosed in Aug 2016 with stage 3 rectal cancer. She had 25 sessions of radiation & Xeloda. She had a surgery which included a permanent colostomy. The tumour was too low, so they removed the sigmoid colon, rectum and anus. This week it will be 5 years since her surgery. She had chemo after the surgery and is monitored at Princess Margaret. She has a CT scan next month.

**[Case #283]:** He is a stage 2 colorectal cancer patient. He has had surgery followed by 6 months of chemo with FOLFOX. He had a 6-month CT scan and is clear of inflammation and has another one in July. He's very interested in ctDNA. He's taking antioxidants and supplements now.

**[Case#266]:** He is preparing for a trip to California for cryoablation and is waiting patiently for that.

**The next meeting dates for 2021 are as follows at 1:00 p.m. sharply:**

Sunday, February 20, 2022

Sunday, March 20, 2022

**Sunday, April 10, 2022** (Easter Sunday is April 17)

Sunday, May 15, 2022

Sunday, June 12, 2022 (Father's Day is June 19)

Sunday, July 17, 2022

Sunday, August 21, 2022

Sunday, September 18, 2022

Sunday, October 16, 2022

Sunday, November 20, 2022

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