



A PATIENT-FOCUSED ORGANIZATION

VIRTUAL NATIONAL SUPPORT GROUP MEETING VIA ZOOM

SUNDAY, April 10, 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](#).

Count Me In with Mary McGillicuddy

Colorectal Cancer Project

The Colorectal Cancer Project is an online research study open to anyone in the United States or Canada who has ever been diagnosed with colorectal cancer, enabling them to share their samples, medical records, and experiences with researchers. Every patient has a unique story that the research community can learn from. Data generated through the project will be de-identified and shared with the aim of accelerating colorectal cancer research by making data freely and widely available to the community.

Q: Are you planning to include a survey about early age onset colorectal cancer?

A: Yes, that's definitely an area of interest for us! We will be utilizing age of onset information to stratify information.

Bum Run: Coming April 24. It's a 5km walk/run to promote awareness of colorectal screening across Canada because we know screening saves lives. It can cure early-stage disease or prevent cancer. It's

taking place in 6 cities virtually, and going live in Toronto and Calgary, pandemic restrictions allowing. All funds raised by Bum Run will benefit CCRAN's patient programs. You can participate as a registrant or support a participant financially. You can also let your friends and family know about the event in order to raise awareness.

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 #296]: He is a 76 year old patient, recently diagnosed with sigmoid colon cancer. He's deciding what route to go for treatment. CEA was 1. His scan recently indicated there is no cancer in the colon wall or tissue, so the polyp removal may have been curative. He had prostate cancer in 2020, and radiation treatment was done for that. His PSA was at 5.05. At the latest appointment he had a drop to 0.84 (2 years ago). There is some concern if he has surgery after radiation for the prostate cancer, there could be issues for him with reconnection if he went for bowel surgery. He felt reassured by the CCRAN members at the meeting and more confident to proceed with surgery.

[New Case #297]: He is a 40-year-old patient with stage 4 rectal cancer. He is starting chemo radiation next Tuesday. His cancer team is at Sunnybrook. The chemo will be Xeloda orally twice per day. The oncologist may recommend IV chemo before or after surgery. CEA around 18. He has two aunts with a history of bladder cancer. His maternal grandmother had breast cancer. His grandmother had 10 children. 6 months ago, he had a mole on his head. He went to the dermatologist and 2 weeks later, the spot was determined to be linked with colorectal cancer. He suggested a colonoscopy. The family doctor did blood work, and there were no symptoms, so they decided to monitor. In November of 2021, he started getting blood in the stool. They decided to do a colonoscopy. He had to wait until February due to a COVID-19 backlog. Total neoadjuvant therapy may be considered which consists of: IV Chemo FOLFOX, plus radiation therapy and then surgery to follow.

[Case #274]: He is a 66 year old, stage 4 patient. He had a bit of liver resected, and it turned out to be a metastasis from colorectal cancer. The cancer is positive for a BRAF V600E mutation. He's on palliative chemotherapy. He has had 12 rounds of chemo, with the last one Nov 12, 2021. He was away all winter in the US and off therapy. He just got back last week and will see his oncologist this week. He did FOLFOX and Avastin. Braftovi is an option in future for him since he has the BRAF V600E mutation. His surgeon said he's in the 95th percentile for the condition because he is doing really well.

[Case #291]: She is a caregiver for a 70-year-old, stage 4 patient. In 2012, he went for colonoscopy and they removed a polyp. It was a cancerous tumour but at stage 1, so no other treatment was required. In May 2021, he went for another colonoscopy, and it turned out he had stage 4C colorectal cancer. He is going to see his new medical oncologist Wednesday. It is a left sided tumour that he has. They are testing for CEA. CEA was at 28 and is now at 1.2. He has peritoneal metastases and a liver metastasis. He's had an excellent response. He has had a 2 month break from FOLFIRI and panitumumab (February 9 to now). He had 12 sessions and started in August. He was having bowel issues due to the Irinotecan chemo in FOLFIRI. He ended up having hydration therapy at home to help with the issues. He will have a new oncologist at Oakville Trafalgar Hospital. CA19-9 is sometimes used to monitor for peritoneal metastases that originate from colorectal cancer. It is usually used for pancreatic cancer marker. He had swelling in his legs. Doppler did not find blood clots. His legs are now improving. His blood pressure has increased while he was off chemo.

[Case #197]: He started chemo again at the end of January. He has had 6 rounds of FOLFOX and 70 rounds of chemo total since 2018. His CEA had climbed while he was off chemo for his lung surgeries. However, after starting systemic treatment again, his CEA has gone from a high of 24 to 11 after 2 treatments and then from 11 to 8 after 4 treatments. His next CEA is scheduled for April 25. He had CT scans last week and the results are back - everything is either stable, shrinking, or gone, proving a good response to FOLFOX. He has no neuropathy. The plan is to continue with treatment and check in with the oncologist after 8 rounds to confirm the continued plan of care. The palliative radiation to his right pelvis has been quite a success. He has no pain and he is not taking any pain meds. His thoracic surgeon is very pleased with his recovery. He will check in again after the next set of CT scans to decide what's next - perhaps some radiation treatment on the remaining couple of spots in his lungs. He did have COVID over Christmas but he saw the respirologist last week and he says his lungs show no sign of long term damage.

The next meeting dates for 2022 are as follows at 1:00 p.m. sharply:

**Sunday, May 15, 2022 Patient Information Session – Treatment of Earlier Stage
Colorectal Cancer**

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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