



***A PATIENT-FOCUSED ORGANIZATION***

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

**SUNDAY, FEBRUARY 20, 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 # 8: MSI High Colorectal Cancer – microsatellite instability high (MSS-High).**

Instability is in the piece of genetic coding. Mismatch repair refers to the MMR genes that stop functioning in the cell. That's how a colorectal tumour becomes highly unstable. It's found in about 15% of colorectal tumours. They are found in all stages of tumours. It is often seen in a hereditary syndrome, such as Lynch Syndrome. You can also have MSI high disease as a result of a sporadic mutation as well. MSI status gives your doctor an idea of how your tumour can behave or be treated. In an MSI- high tumour, immune cells can be hovering around the tumour. This type of tumour has a great response to immunotherapy treatments like pembrolizumab. In the metastatic population MSI-high is found in about 5% of patients. That means most patients (95%) do not respond to immunotherapy. It doesn't necessarily have the same side effect profile as other forms of chemotherapy. MSS (microsatellite stable) colorectal cancer are referred to as "cold" tumours. Tumours should be tested for MSI status because it can inform treatment options. Testing can happen during or after surgery via immunohistochemistry (IHC) testing.

**Cabozantinib** targets 3 pathways (VEGFR, MET and AXL). It's an oral drug and works by blocking the action of proteins called tyrosine kinases (RTKs).

**Durvalumab** is approved in kidney cancer and bladder cancer. It's a type of Immunotherapy administered via IV.

These 2 drugs are being studied in a clinical trial in an MSS population. At this University of Kansas study, patients had received at least 2 lines of therapy. 29 patients who were MSS. Overall response was 27.6%, partial response 20.7, and disease control rate 86.2%, progression free survival was 3.8 months. Overall survival was 9.1 months. For wild type patients n=12, overall response rate was 50%, the disease control rate was 83.3%. Progression free survival was 6.3 months. Astoundingly, overall survival was 21.8 months.

**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.

CCRAN will be stratifying support groups in the near future by age and stage, so that patients can relate to each other and can discuss common concerns. We will be offering a training and certification course and commence afterwards.

## 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 #289]:** She was unexpectedly diagnosed last Dec, 2 weeks after her 60<sup>th</sup> birthday. The time from colonoscopy to coming home from surgery was only a month. She had early stage 3 disease. The cancer is in 2/36 nodes. Chemo will be starting the beginning of March. She has two daughters, 27 and 25 years old. They lost their dad 5.5 years ago, and their grandmother 2.5 years ago, so the diagnosis is hard on them. Her eldest daughter is a rock, but the youngest can't face it. She is struggling with it right now. This cancer patient is a strong woman and a fighter. She encourages everyone to keep believing and fighting. She's been doing painting, journaling, and poetry writing. She shared a painting of a light house with an uplifting message. Cancer is treatable and we're all going to get through it. Retired from 31-year profession in 2020 and she's been looking for her purpose, and just before the diagnosis, she realized her purpose and she wants to be a part of CCRAN and would like some training to be a councillor. She's looking for contributions for her book. Other patients were very supportive of her viewpoint. She was wondering about cost of meds. Most medications for treatment are covered through the province, but side effect medication can be through insurance or out of pocket.

**[New Case #291]:** 2012 had a cancerous polyp removed. He missed some colonoscopies due to COVID. The last colonoscopy was 2017 (no findings), and then another in May 2021. He was adjusting pills for blood pressure, and they have side effects on GI function, so they didn't realize the symptoms were from colorectal cancer. Eventually they did a colonoscopy and found out he was stage 4. He's had 12 chemo treatments and 2 radiation treatments. He is on panitumumab and FOLFIRI. As far as side effects, he was unable to sleep for 48 hours, and had neuropathy, bleeding, and bowel issues. These are likely from irinotecan. He had to sleep in a lazy boy for a period of time due to pain and he can sleep again in bed now, so it has improved. He will be doing a 2-month rest now from chemo. He has blood clots in his

legs. He hopes they can control the side effects. The first scan showed 50% shrinkage. Things seem stable and the liver has very minute spots that are left. Still has cancer positive lymph nodes and the tumour in the colon. He has a left sided tumour at the rectal sigmoid junction which is RAS Wild type. His metastases are in the peritoneum and liver. He would like to have surgery. Surgery may be an option with good response to chemo. Generally, surgery requires being off for a few weeks. Atropine was suggested with irinotecan. Perhaps CT can be done in 1 month to assess prospects for surgical resection. May also be possible to lower dose of chemo slightly (by 5%) to improve quality of life. Their sons are reluctant to go for screening (40 and 37) but have been urged to do so.

**[New Case #293]:** Parents of an active case. Their daughter's diagnosis has hit them very hard. He had a small polyp removed and will have a follow up colonoscopy in 5 years. He will do yearly FIT testing. They're so grateful their daughter found CCRAN. There is family history on Mom's side – there were probably undiagnosed cancer patients. Most of the siblings had major issues with bowel and gut, with cancer and surgeries. They passed younger than their time. They have both signed up for the Bum Run and CCRAN is very grateful for their help.

**[New Case #290]:** She is 38 years old. Stage 4 Left sided primary rectal cancer with liver metastases and probable lung metastases, which later turned out not to be cancerous. When she was diagnosed, she had a hard time telling people. She put it in a letter mostly to work colleagues and called it Hayley's village. She comes from a huge family and are there for each other. COVID makes it much harder to support since you're sitting in a parking lot instead of in the office together. She got all her bad news in an oncologist's office by herself. That's why she feels that support groups are especially important. She was diagnosed in May 2021 after vague symptoms like fatigue and abdominal cramping. She brushed them off because she was a busy mother of a 3- and 6-year-old and a full time RN. The first symptom was blood in her stool. It escalated quickly and was filling the bowl. She went to her family doctor and the doctor did a rectal exam and sent her for a colonoscopy. About 2 weeks after that she got her diagnosis. She did FOLFOX chemo for 6 cycles and had excellent response. She did radiation as well. Her surgeons asked her to go off and she did a LAR (Lower Anterior Resection) just before Christmas. She was positive in 5/12 nodes. She also went for liver surgery and only scarring was found during that surgery as a result of chemo. The scar tissue was removed. Post surgery she is no evidence of disease in the liver. The next stage is clean up chemo. She is RAS Wild type. All ages with colorectal patients have their own realities, but for early age onset patients, it's a very different experience. She is pleased with the medical communication and the oncology team. She has had a career as a palliative care nurse. Changes have been night and day as to staging – stage 4 is much more treatable. Treatments for liver and lung mets are much more available and possible. She's excited what the next 7 years will bring. HAIP and HIPEC came about through advocacy and are exciting and important cancer treatment options.

**[New Case #292]:** She is 45 years old and has stage 3 colorectal cancer. They did a colonoscopy due to blood in stool. Her doctor did a rectal exam. They thought it was internal hemorrhoids but sent her to a surgeon. She then did a CT scan, and the lymph nodes were borderline. They were worried about the liver as she's had 2 hemangiomas, which did not grow much with the new CT scan. They did an MRI, and the hemangiomas were confirmed. They did a sigmoid colon resection, and she was at Humber River for 2 days and went home on the 3<sup>rd</sup> day. It was a laparoscopic surgery. Pathology should take 2 weeks to come back. 9 lymph nodes were positive out of 22. She is feeling very emotional about the news. She will be starting FOLFOX chemo, likely 6-9 cycles. Then she will be under surveillance for the next 5 years. She is having some rib pain on the right side (likely unrelated). She wonders if she should go to a bigger centre for chemo, but for the most part chemo can be done everywhere. She has an excellent surgeon. She has 3 kids, a baby, 23, and 25 years old. She wonders about screening for them. CCRAN will help.

**[New Case #294]:** She's on 4<sup>th</sup> FOLFOX treatment and is exhausted now. They're mopping up, so it should be less than 12. Usually it's between 6-9 sessions.

**[Case #260]:** She has stage 4 colorectal cancer. Her nana died of colon cancer at 54. Thought she had cancer in her reproductive organs because she was having issues. She felt something pulling on her intestines. At the colonoscopy date they thought they wouldn't find anything. Jessica is diagnosed with AFAP. She had 30 polyps and 2 tumours. They were unsure about staging. They found lung nodules. The biopsy was inconclusive. She did 12 rounds of FOLFOX. She has been thriving all year. She's doing biking, running, and walking. She's spending as much time as she can with her 3-year-old daughter. In 8 months, she got her surgery. She's located in Vancouver. She was originally inoperable. She had such a good response that she was able to get whole colon removed. She has a temporary ileostomy bag. Her removal surgery J pouch removal was delayed due to COVID. She's not having a lot of issues about not having a colon. She had a wedge resection in lungs. The nodules were confirmed as cancerous. She always had 5 lung nodules although she thought there were only 2. The other 3 were smaller. In BC she doesn't qualify for SBRT or cryoablation. The last surgery was cancelled as the metastases were located too deep in the lung tissue. She has a PET scan this Saturday, and is scheduling SBRT on her lungs, although it isn't normally approved in BC. She is very excited for the future and hopes to have no remaining disease after the SBRT. Her sister was diagnosed in Australia. They found 24 precancerous polyps. She also is AFAP. Her brother is 32 with 2 non-cancerous polyps. It took 9 months in BC to get the colonoscopies done.

**[Case #208]:** She was diagnosed at 38. She has a 3cm terminal brain tumour. It was the last thing she was expecting to happen. In 2016 her doctor thought she was ok, and she refused a colonoscopy. She was exhausted and had lower rectal pain. Her family thought she was being dramatic, and nothing was wrong. She got x-rays and was sent home. They did blood tests, and nothing showed up. Her CEA was normal. Eventually, she started having rectal bleeding and went for colonoscopy. By then it was stage 4. LAR (Lower Anterior Resection) surgery was done. They did FOLFOX. She lost feeling in her feet from the side effects. She had metastases in her lungs. She had SBRT and two lobectomies. She had Incontinence and couldn't leave house for 2 years. They removed part of the rectum surgically. They thought they were getting to a good place, and she found out she had primary thyroid cancer. They removed part of the thyroid. Later colon cancer spread to her brain. She had a blood clot in the lung, and she was hospitalized. She's now on oral blood thinners with less side effects. They did external beam radiation to "burn out" the brain tumour. She's having body swelling due to steroids. For the thyroid she had to be off steroids which lead to her being unable to walk. Has started a light sleeping pill and is now better rested and able to walk to the washroom. She will be doing whole brain radiation to shrink the brain tumour which has spread throughout her brain. After 5 fractions she will be starting systemic treatment with FOLFIRI and bevacizumab (Avastin). She has little metastatic disease in her lungs now. This treatment may also address her metastatic thyroid disease. Avastin crosses the blood brain barrier which means it might be able to reduce the burden of the disease in the brain. Doctors have given her 6 months to 2 years to live. She has a 29-year-old son. She really wants her son to go for a colonoscopy. She has a family history but not a hereditary syndrome. She has started a Bum Run team. CCRAN is very grateful for her support.

**[Case #285]:** She was diagnosed last year at 36. Has lymph nodes positive, spine, and liver. Originally, they thought it was lymphoma, but it was confirmed to be colorectal cancer. She just finished her 11 FOLFOX and panitumumab. Will be doing CT March 9. The last one in December was very good (decrease of 50-70% in tumour size). She will be taking a 2-month break. Surgery is not an option for her. She will be taking the CT to another oncologist. Her CEA has come down from 75 to 3. Oxaliplatin will be lowered due to neuropathy in her feet. It was 80% in last two rounds. The neuropathy has been better since the change. She's been tolerating treatment well, and she's feeling quite well at the

moment. She has 2 kids, ages 6 and 9. She had 5 days of radiation before starting chemo. She is taking bone strengthening meds every other round. She has changed skin cream for dry skin. She would like to go to South Africa for a month during the chemotherapy break. Her doctor will have a look for clinical trials. She could consider Princess Margaret for a second opinion and perhaps for research options.

**[Case #269]:** She was diagnosed stage 4 rectal cancer, with metastases to her liver at 57 years old. She had never had surgeries before and was otherwise healthy. She was diagnosed 6 months before COVID, and the remainder had to be navigated during COVID. She was telling her doctor there was blood in her stool and her doctor thought it was hemorrhoids or a fissure. She tried a suppository. She decided to leave her workplace and got a diagnosis 6 months later. She was with her current doctor 25 years. In 3 months, she did a rectal exam and colonoscopy. It was graded stage 3 originally. They recommended capecitabine pills and radiation. She got a second and third opinion and paused for 5 months. Her new oncologist recommended a PET scan. That was how they found metastases in the liver. She started chemotherapy in March of 2020 with CAPOX and Avastin. She did many homeopathic modalities. She did 6 months of treatments and blood tests and scans. They did watch and wait and, in the fall, they found something on a scan. They did sigmoidoscopy and took tissue that had cancer cells from the bowel. They scheduled rectal surgery in January. She recovered well. Then they were dealing with the liver. She did well with 5FU. She has been a great self-advocate and has taken an active role in her treatment. She did liver surgery in September this past year. It was major surgery at Vancouver General. She's now 5 months out from surgery. She's taking it one day at a time. Her monitoring PET scan showed no signs of disease. She has a temporary ostomy bag, as they removed the rectum and is hoping for a reversal. She had a colonoscopy last week. She did clean up chemo with 5FU to be sure she's done everything possible. The next thing will be learning to use her bowels after the reversal. She's looking forward to getting back to normal and maybe travelling. Her next follow up will be in May.

**[Case #227]:** Her tumour would have started at 36 years old. She was diagnosed at 46. Her story is on video on the CCRAN site. She invites everyone to have a look. She is MSI high and was diagnosed at stage 4 with colon cancer. She did first line chemotherapy plus Avastin, and it did not work. Her oncologist wanted her on immunotherapy, to which she responded much better. Everything shrunk. She had liver and peritoneal metastases and a piece of the original primary tumour. Her last treatment was May of 2020, and she has had clean scans ever since. She was going to have a colostomy reversal, but it was cancelled due to COVID. She was also going to travel, which was postponed. She suggests that those with disabilities like cancer may be eligible for disability tax credits, particularly with colostomies or ileostomies. She also encourages participation in Bum Run to help spread awareness of screening and help CCRAN.

**[Case #197]:** It took him 4 years to get to surgery of both his lungs. He's a stage 4 patient with metastases in lungs and retroperitoneum. He's had 64 rounds of chemotherapy. He took a couple of months break to prepare for surgery. He met a lung surgeon through CCRAN. He was originally diagnosed in 2008 with stage 3 rectal cancer and was no evidence of disease for 10 years. Monitoring was the reason he knew his cancer had returned, since he had no symptoms. He is currently in treatment since 2018. It came back at stage 4, and he's had 66 rounds since its return. He had 2 successful lung surgeries. He caught COVID (Delta variant) around Christmas and it was very tough. He had inflammatory response in his lungs. He's switched from FOLFIRI and now does FOLFOX. He has a pelvic metastasis, and a small amount of disease left in his retroperitoneum. He has no signs of neuropathy and is finding FOLFOX more tolerable than FOLFIRI. He had metastases to both lungs and a lymph node in the retroperitoneum. He had radiation to the pelvis. The lung surgeries have likely added a lot of time to his life. The lymph node is not life threatening. It's important to be assertive and advocate for your choices and rights.

**[Case #283]:** He did a colonoscopy in 2017 and everything was fine. In 2020 he asked for a physical and his family doctor sent him for bloodwork and called two days later and said his hemoglobin is low. She sent him for another test and then a colonoscopy. He was diagnosed with cancer. He went for surgery and had stage 2A low grade cancer. The lymph nodes were fine. They invited him to be in a clinical trial. He was ctDNA positive. He did 12 rounds of FOLFOX. The CT scan was ok. He had issues with numbness of the fingers and toes. Neuropathy generally takes some time to resolve, often months and sometimes years. For a few unlucky patients there may be residual neuropathy permanently, but most improve with time. The group suggests keeping warm, as being cold tends to make the sensation feel worse.

**[Case #164]:** She continues to do very well and just passed a significant milestone - it's been 5 years since she had her surgery and got her colostomy. She has a CT scan at the end of February and is hoping for good results.

**[Case #295]:** On March 28th, 2022 it will be three years since he completed his 10 sessions of adjuvant chemotherapy. His last test results including CEA, abdominal CT scan and CXR were all negative last year.

**Here are some of the exciting events at our upcoming meetings:**

**Sunday, March 20, 2022:** Patient Education Session – Treatments of Stage 4 Metastatic Colorectal Cancer with sessions with 4 experts:

**Dr. Eric Chen**, The Medical Management of Metastatic Colorectal Cancer

**Dr. Calvin Law**, The Surgical Management of Colorectal Liver Metastases

**Dr. Anand Govindarajan**, The surgical Management of Colorectal Peritoneal Metastases

**Dr. Aaron Pollett**, The Utility of Biomarker Testing & The Importance in Helping to Guide Treatment  
Please RSVP to [Sheila.v@ccran.org](mailto:Sheila.v@ccran.org) to attend.

**Sunday, April 10, 2022:** Count Me In Presentation and Patient Support Meeting

**Sunday, May 15, 2022:** Presentation by **Rachel Reid**, Registered Dietician on Foods for Life

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

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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