My Dear Friends,

I am pleased to share CCRAN’s 2023 Summer Newsletter with you containing exciting updates, the result of which are the tireless efforts of CCRAN’s dedicated and committed staff.

First and foremost, welcome to our new bilingual website: www.ccran.org! This is a comprehensive hub containing evidence-based information and resources designed to improve the patient and caregiver journey as well as help to inform the Canadian seeking information on primary colorectal cancer prevention.

I am delighted to announce the official launch of our new groundbreaking tool, “My Colorectal Cancer Treatment Side Effects”. This innovative resource aims to empower patients, caregivers, and healthcare professionals alike, by providing valuable information on treatment-induced side effects for every colorectal cancer drug therapy.

CCRAN was privileged to have had 360 registrants for our inaugural Biomarkers Conference! The conference not only fostered collaboration and knowledge exchange amongst the various tumour type patient advocacy groups, clinicians, pathologists, patients and more, but also kindled hope for the future of cancer treatment. I am also proud to report the resounding success of our “My Colorectal Cancer Coach” training and certification conference, which equipped 11 dedicated individuals with the evidence-based information and skillset to support patients and caregivers undergoing the colorectal cancer journey.

And did you hear about the inaugural debut of CCRAN’s “Jumbo Colon” at this year’s Bumrun? It was a smashing success as was the national bumrun campaign! CCRAN raised well over $286,000.00 thanks to you all. Thank you for making it such a successful campaign. We couldn’t have done it without you all.

Stay tuned as we are now launching our newest program,” My Colorectal Cancer Companion,” an initiative that focuses on providing peer to peer support for the colorectal cancer patient, according to similar demographics, case details, and life experiences, enhancing the benefits received through that peer support.

Please click on any of our articles to learn more about our evidence-based programming and the wonderfully dedicated medical professionals we have supporting our programs. Thank you for choosing CCRAN. We are privileged to have you as a member.

SCREEN IT. TREAT IT. BEAT IT.
Together, my friends, anything is possible!

My Very Best To You,
Filomena Servidio-Italiano
President & CEO, CCRAN
I am not one to share openly personal situations but if I can help to improve someone’s quality of life or even save a life, I am all in! Last September, I was unfortunately diagnosed with stage IV colorectal cancer. Two surgeries later (colon and liver), 7 rounds of chemotherapy with 5 to go, I should be in very good shape health wise. I have been very lucky to have the loving support from family and friends. Along with a positive attitude and an amazing healthcare team, I am pulling through this nightmarish stage in my life.

I am reaching out mainly to raise awareness to a disease that is the second leading cause of cancer death in Canada. The good news is, it’s very curable especially if caught early. I would like to use my lessons learned to help people facing a similar diagnosis.

- Get to a doctor ASAP if something is not right down below (blood in toilet bowl or stool or change in bowel habits) – I thought I had internal hemorrhoids and delayed getting to a doctor by a couple months.
- Be your own advocate and DO NOT be afraid to follow up and even ruffle a few feathers if you have to.
- Get a colonoscopy. I had my first one at 45 and then at 46. I should have had one at 51, (I am 52 now) but I was unaware and nobody followed up. This was my miss!! Colonoscopies are easy. If you have questions contact me please.
- Don't think it can't happen to you. As we age, more people we know have health issues and scares and unfortunately even die. Our families and friends need us and we need them.

Personally, I do think if I had acted quicker, I could have caught it prior to turning cancerous or even during stage I or II. It is so sad, but 50% of colorectal cancer diagnoses are made in the later stages.

Through all of this I was introduced to CCRAN – Colorectal Cancer Resource & Action Network, led by Filomena Servidio. To say she is amazing is an understatement. Along with my formal healthcare team, she was able to put my situation into simpler terms. She was also able to give additional guidance and direction and has an amazing patient advisory council to lean on. She was available to me 24/7 and Sunday morning chats were not out of the ordinary. She and her team gave my family and I the needed support and reassurance that things were on track and that there are many options for me. I could not imagine going through this without CCRAN's support.

It’s been a roller coaster ride over the past 7 months. I have learned a lot about life and what really matters. I have never received so much love and given so much in return.

MIKE SCHILLER
STAGE IV PATIENT
CCRAN's inaugural Biomarker Conference was an absolute success! We are proud to have brought together patient perspectives, identified pertinent challenges and opportunities for timely biomarker testing/reporting, and stimulated discussions on the utility of ctDNA and the value and feasibility of CGP as future standards of cancer care in Canada. We believe our pan-tumor approach to the Conference highlighted that there are more commonalities than differences across cancer types, and that working collectively and collaboratively we can unleash the full potential of precision oncology. We have been humbled by the support we have received across cancer types.

CCRAN intends to act upon the outcomes of the Conference, and we will do so by capturing these outcomes in a publication, issuing a call to action to see that there is a biomarker guidance document in place for all cancer types, and continuing to advocate for equitable access to advanced personalized diagnostic approaches. Rest assured, we won’t stop until we’ve moved the needle forward on any and all testing that can potentially improve an advanced cancer patient’s outcomes.

Thank you to our supporting sponsors!

Recommended Reading:

"On the Other Side of TERMINAL: Take Back your Life from Cancer NOW" by Allen Chankowsky

On the Other Side of TERMINAL is a powerful book that shares author Allen Chankowsky’s inspiring and deeply authentic account of his 31-year relationship with cancer. Shattering all expectations, Allen bravely exposes the depths in which he struggled to overcome his rare form of stage IV cancer. With a palpable sense of unmistakeable urgency, his unique style skilfully illuminates the emotional strength it takes to manage the realities of living with a world-crushing diagnosis.

To learn more or to purchase the book, click here.
LOOKING FOR SUPPORT OR INFORMATION ON COLORECTAL CANCER?

Please join Colorectal Cancer Resource & Action Network (CCRAN) for a patient/caregiver information and support group meeting

- Learn about colorectal cancer resources
- Meet others on the same journey who are willing to assist
- Be informed, feel supported, and become educated about novel colorectal cancer therapies
- Participate in expert presentations
- Access monthly treatment and clinical research updates
- All stage-patients and their caregivers are welcome!

Beginning in September, CCRAN’S meetings will be offered in four groups to better support the unique needs of each population:

- Under 50 years old, early stage disease
- Under 50 years old, advanced stage disease
- Over 50 years old, early stage disease
- Over 50 years old, advanced stage disease

Please contact Cassandra Macaulay at cassandra.m@ccran.org to RSVP before a meeting or for additional details.

The virtual meeting dates for 2023 are as follows at 1:00p.m. EST sharply:

- Sunday, August 20th
- Sunday, September 17th
- Sunday, October 15th
- Sunday, November 19th
In response to positive feedback from CCRAN’s recent pan-tumor Biomarker Conference, CCRAN has proudly expanded the scope of the third fall symposium to include additional tumor types in which rising incidence of early-age onset cancer has been documented.

We truly believe that there are more commonalities than differences across tumor types; and that by working collegially and collaboratively with partners in multiple cancer types, we will be more impactful in affecting change.

The tumor types which will be addressed at the EAOC Symposium, in addition to colorectal cancer, are:

- Lung Cancer
- Breast Cancer
- Cervical Cancer
- Ovarian Cancer
- Pancreatic Cancer
- Gastric Cancer

Day 2 of the Symposium will focus exclusively on early age onset colorectal cancer.

VITRAKVI® (larotrectinib) is now covered for eligible patients in:
- Manitoba
- Saskatchewan
- New Brunswick
- Quebec
- Ontario

VITRAKVI® is a precision medicine for locally advanced or metastatic patients with an NTRK gene fusion and offers an additional line of therapy.

Our hope is to see additional provinces and territories come on board in the near future. Stay tuned to CCRAN’s social media pages for future updates. If you have an NTRK gene fusion and would like more information on the eligibility criteria, please reach out to Filomena or Cassandra at cassandra.m@ccran.org

DRUG FUNDING ANNOUNCEMENT!

2023 EARLY AGE ONSET COLORECTAL CANCER VIRTUAL SYMPOSIUM

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"My Colorectal Cancer Consultant" is an online tool designed by CCRAN to provide advanced colorectal cancer patients with potential treatment options that they can discuss with their treating oncologist.

Patients are guided through a series of questions requiring their pathology report. At the end, they will receive a personalized 39 page report that outlines the potential treatment options that may be appropriate for them based on their individual diagnosis (biomarker status). The four highly renowned medical experts pictured below have graciously and generously agreed to represent the various disciplines in the management of the disease and have reviewed and endorsed the algorithms that form the basis of this online tool.

Following the success of this tool, CCRAN will be collaborating with Dr. Mary De Vera and the team at the University of British Columbia on research that will provide insights on CRC patients' knowledge of biomarker testing.

This tool has been successful in helping patients have thoughtful discussions with their treating oncologist by providing them with evidence-based information on the potential treatment options that may be available for them. It also encourages informed and joint decision-making between the patient and their treating oncologist. Check out the "My Colorectal Cancer Consultant" online tool on our new website ccran.org with both English and French versions available.

Thank you to our supporting sponsors!
"My Colorectal Cancer Treatment Side Effects" focuses on colorectal cancer drug-induced side effects. Patients who will be, or patients who are, actively undergoing drug therapy often feel the need to seek out information in respect of treatment-induced side effects to become acquainted with the actual side effect, cause, or remedy. Patient awareness of treatment induced side effects (be it from a chemotherapeutic, biologic, or immunotherapeutic) can have a significant impact on the patient's quality of life.

To assist patients and caregivers with the management of treatment-induced side effects, “My Colorectal Cancer Treatment Side Effects” provides the user with an alphabetized list of treatment-related side effects, and presents the user with the following information in respect of that side effect:

- Description of the Side Effect
- Cause of the Side Effect
- Symptom(s) of the Side Effect
- Remedy / Potential Treatment

CCRAN’s hope is that providing education about treatment-induced side effects and their potential remedies will have a significant impact on quality of life and patient outcomes. We encourage open and thoughtful communication between patients and their treating oncologist and urge patients to share any early signs of treatment-induced adverse events with their care team.

We believe this program will be of utmost importance in helping colorectal cancer patients and caregivers who access evidence-based, reliable, and accurate online information with respect to the management of their early and later stage disease.

Check out "My Colorectal Cancer Treatment Side Effects" online tool at www.ccran.org/my-crc-treatment-side-effects

The following highly renowned experts have graciously and generously served as the consultants for the development of this program, as they have reviewed and endorsed the content:

Dr. Eric Chen
GI Medical Oncology

Dr. Michael Raphael
GI Medical Oncology

Dr. Stephanie Snow
Medical Oncology

Dr. Jennifer Spratlin
Medical Oncology

Laura Minard
Clinical Pharmacy

Thank you to our supporting sponsors!
In May 2023, 11 dedicated and compassion individuals participated in CCRAN's 2023 My Colorectal Cancer Coach Training and Certification Conference over two weeks. Cancer Coaches learned from experts across the continuum of colorectal cancer care who equipped them with evidence-based knowledge, shared knowledge and perspectives from their own experiences as colorectal cancer patients or caregivers, and put their skills to the test with mock coaching scenarios. A heartfelt thank you and congratulations goes out to all of CCRAN's certified Cancer Coaches!

CCRAN's My Colorectal Cancer Coaches stand ready to help guide, support, and inform patients and caregivers as they navigate their own cancer journeys. Would you like to receive one-on-one support and information from our Cancer Coaches? If so, please email cassandra.m@ccran.org.

CCRAN is pleased to introduce our 2023 Colorectal Cancer Coaches

MY CRC PREVENTION COACH
Marcelino Dolores

MY SCREENING & FRENCH CRC COACH
Frank Pitman

MY EARLY-STAGE CRC COACH
Catherine Mifsud

MY YOUNG ADULT CRC COACH
Hayley Painter

MY LUNG METS & PSYCHOSOCIAL COACH
Jessica Dasler

MY PERITONEAL METS COACH
Cathy Fox

MY LIVER METS & CHEMO SIDE EFFECTS COACH
Steve Slack

MY OSTOMY COACH
Robin McGee

MY BIOMARKERS COACH
Cassandra Macaulay

MY GENETICS COACH
Roslyn FitzPatrick

MY NGS & CLINICAL TRIALS COACH
Filomena Servidio-Italiano

Thank you to our supporting sponsors!
**CALL FOR RESEARCH PARTICIPANTS!**

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**DIAGNOSED WITH COLON OR RECTAL CANCER IN THE LAST 5 YEARS?**

You’re invited to participate in *Colorectal Cancer Patients' Perspectives and Attitudes Towards Biomarker Testing (OPTION)*

Participation will involve:
- 10-15 mins survey
- 1:1 interview via zoom for selected participants (compensation offered)

[https://tinyurl.com/OPTION-biomarker](https://tinyurl.com/OPTION-biomarker)

If you have any questions or concerns, please reach out to the study coordinator at etongol@student.ubc.ca

This UBC study is undertaken by Dr. Mary De Vera (Principal Investigator) and Elijah Tongol

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**CCRAN'S SOCIAL MEDIA**

CCRAN is active on Facebook, Twitter, Instagram, LinkedIn, and Pinterest!

We invite you to visit, follow, comment, and share our posts, which we believe are relevant to the colorectal cancer community and others!

By following CCRAN on social media, you can stay up to date with the latest news in CCRAN's programming, important CRC treatment & research updates, and so much more!

Follow us at @ccranorg or click on the icons below to view CCRAN's respective pages.

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**Colorectal Cancer Patient’s Perspectives and Attitudes Towards Biomarker Testing (OPTION) Study**

CCRAN is proudly collaborating with Dr. Mary De Vera and team at the University of British Colombia to explore CRC patients’ knowledge and understanding of biomarker testing, including the facilitators and barriers to access, and the utility of results (e.g., to guide treatment).

If you have been diagnosed with CRC in the last 5 years, please consider taking this short online survey to participate in our patient-oriented research. Some participants will also be invited to provide an in-depth interview via phone or zoom.

To take the survey, please click [here](https://tinyurl.com/OPTION-biomarker)
From April 30th to May 14th, over 1,000 people took part in the 12th annual Bumrun and made it the most successful Bumrun yet! Participants in Toronto, Halifax, Calgary and Virtually walked and ran to raise awareness of colorectal cancer screening. This was the first year that Halifax hosted a live event and participants enjoyed a bright sunny spring day at Sullivan’s Pond. Toronto and Calgary runners and walkers returned to Queen’s Park and the Foothills Medical Centre grounds to again take part in the 5K walk/run and enjoy the festivities. The Virtual event attracted participants from across Canada who were responsible for raising a staggering total of over $64,000.

CCRAN’s new Jumbo Colon was featured at the Toronto and Halifax events and this magnificent awareness exhibit was a big hit with all the Bumrunners. We had a tremendous turnout for all the events, and we cannot wait to see how it grows in the future. In total, CCRAN raised a total of over $286,000. Thank you again for your extraordinary effort, support, and participation! We are grateful to our patients, caregivers, survivors, long-time supporters, family, and friends who made this year’s Bumrun a huge success. We look forward to seeing you in 2024!
Summertime has long been known as BBQ season, but grilling can bring on a new meaning and a potential fear to those fighting cancer or who want to implement dietary changes for cancer prevention.

When meat is heated above 300°F or is hit by an open flame, it forms heterocyclic amines (HCAs) and polycyclic aromatic hydrocarbons (PAHs). These chemicals may mutate DNA, leading to possible cancer risk. While getting that great char may add flavour, it also adds possible carcinogens, which definitely puts a damper on summertime grilling.

Let’s be honest, we know how difficult change and giving up something you love can be. I know from working with many clients that there is only so much many people are willing to give-up/restrict – and too much restriction can psychologically backfire as it can lead to hyper fixation.

So, it’s important to be realistic with nutrition recommendations, and luckily, there are tips to help you grill more safely and reduce your risk! Several studies have found that marinating meat before grilling greatly decreases its carcinogenicity.

For example, marinades containing lemon juice, rosemary, as well as sources of vitamins E (e.g., soybean oil) and C (e.g., chili pepper, cranberry juice), decreased the PAH levels by up to 70%! The addition of vegetables, pepper, onion, and garlic with the meal has also been shown to help mitigate the effects.

It’s also important to note that when it comes to diet – consistency, and what you’re doing 90% of the time is what is going to matter most, and, there are many things that are possibly carcinogenic. This doesn’t mean we should be scared of many things (disordered eating can be more harmful than any one food), but think of the overall lifestyle as what is going to make the biggest impact. What can you implement as consistent habits that will help reduce risk? Increase fruits and veggies, increase fibre, increase calcium foods, physical activity, etc., and practices that may increase risk? Think of them as once in a while treats.

CCRAN’s National Registered Dietitian Felicia Newell (RD, MSc). Felicia is available for free support for CCRAN members – reach out to felicia.n@ccran.org any time.
We are very pleased to introduce CCRAN's new website which is more intuitive, more user-friendly, and contains more support, education, and advocacy resources for colorectal cancer patients and caregivers across the country.

CCRAN's new website is bilingual and our hope is to serve the unmet needs of Canada's French-speaking population with resources accessible in both official languages. With new features like the "My Colorectal Cancer Treatment Side Effects" tool and a live chatbot for the Early Age Onset Colorectal Cancer community, we are sure you will learn something new and enjoy the experience while at it.

To access the new website, please visit www.ccran.org

PATIENT TESTIMONIAL

"So much advancement CCRAN has made in such a short time. It's astounding that so many experts joined in to provide support. It's the strong, knowledgeable, focused, passionate and dedicated leadership that brings this flourishing. More than ever, the services this Association provides are needed today!

Bravo Filomena, your attitude, focus and inspiration is making a huge impact on everyone who joins and on others who know where to go when they need support and guidance."

- Chryss Christou
Feedback from CCRAN’s Young Adult Patient Advisory Council has inspired the development of a new peer-to-peer support program!

Sometimes the best therapy for cancer patients and caregivers is just talking with someone else who has been in your shoes. We understand that connecting with someone who has similar demographics, case details, and life experiences enhances the benefits received through peer support.

As CCRAN develops this new program in the coming months, we will reach out to our membership to determine who is open to connecting with peers and will document pertinent information. We will get a little personal – each patient is unique, and obtaining more information will allow us to facilitate stronger connections.

Our hope is that this program will help to ensure that no one feels alone as they navigate their colorectal cancer journey.

This new program will differ from, and be in addition to, the My Colorectal Cancer Coach program, which provides education and support from trained and certified Cancer Coaches. Time commitment from participating peers will be minimal.

Peers will be paired with patients according to:
- Disease stage and biomarker status
- Age, gender, marital status, and demographics
- Ethnicity
- Sexual orientation
- Treatment journey
- Geographical location
- And so much more...

Stay tuned as we launch our national program to address the needs of our newly diagnosed and not so newly diagnosed colorectal cancer patients and caregivers across Canada.
Lonsurf® + Bevacizumab
Patient & Caregiver Perspective Survey

Are you a metastatic (stage IV) colorectal cancer patient or caregiver? If so, we could really use your help!

Lonsurf® in combination with Bevacizumab, is currently under a funding review in Canada for the treatment of metastatic colorectal cancer, and CCRAN is completing a Patient Evidence Submission to ensure the patient perspective is provided to support the decision. All Stage IV colorectal cancer patients and/or caregivers are eligible to complete the anonymous survey, which just may help to improve access to this therapy for metastatic colorectal cancer patients in Canada. Help us ensure the patient voice is heard!

To take the survey, please click [here](#).
Welcome to CCRAN’s series on Low Anterior Resection Syndrome, called LARS, by Robin McGee, CCRAN’s My Ostomy Coach

“I thought once the bag was gone I would go back to normal”

“It was so unpredictable. I would never feel properly empty.

I would go all the time - sometimes over 20 times a day.”

“I have so much more gas now - I am glad to have a dog I can blame it on!”

If you have had surgery for rectal cancer, chances are you can relate. Taking cancer out of the rectum can lead to damage to the way we poop. Many of us are surprised to still have symptoms for years after surgery, like clustering (many bowel movements in a short period). Truth is, 80% of us have Low Anterior Resection Syndrome or LARS. This is a condition of “disordered bowel function after rectal resection, leading to a detriment in quality of life.”

CCRAN is listening. Many ask for support as they adjust after surgery. So we will be starting a newsletter series all about LARS: having it and managing it. Watch this space!

COUNT ME IN:
"THE COLORECTAL CANCER PROJECT"

CCRAN is proud to be an advocacy partner for the Colorectal Cancer Project, Count Me In. Over 300 people have already said “Count Me In,” 44 of whom are from Canada. The Colorectal Cancer Project works by asking patients diagnosed with colorectal cancer to participate by sharing saliva, blood, and/or stool samples, copies of their medical records, and possibly a portion of their stored tumour samples.

Patients can participate by visiting the website below to sign an electronic consent form. With consent, Count Me In will send a sample collection kit, as well as locate their medical records and provide any resources necessary for the physicians and hospital staff to send the materials. This approach allows patients who don’t currently have the opportunity to participate in this type of research to say “count me in” and participate in research directly.

This much larger group of patients will help accelerate research in colorectal cancer by sharing samples and clinical data that at present remain understudied. This approach could lead to more rapid discoveries and help identify new therapeutic strategies.

To learn more about the research being done or to sign up for participation, visit Count Me In at www.colorectalcancerproject.org
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CCRAN is governed by a professional Board of Directors who judiciously counsel CCRAN on legal and ethical matters of integrity as well as ensure the effective running and management of the organization.

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Patient Advisory Council Members advise CCRAN on programs and initiatives that can positively impact the colorectal cancer patient population in Canada.

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Mr. Robert Hamilton
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Young Adult Patient Advisory Council Members advise on the development of our Patient Programs to support the Young Adult Colorectal Cancer Population.

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