A PATIENT-FOCUSED ORGANIZATION

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## A Message from the CCRAN Team

This is the team of dedicated individuals who ensure that patients and caregivers gain access to a **'SEA'** of services: **SUPPORT, EDUCATION AND ADVOCACY.** 



**NATIONAL PROGRAMS** 

Frank Pitman
SENIOR MANAGER,



Filomena Servidio-Italiano PRESIDENT & CEO



Grace Malito
MANAGER, ADMINISTRATION
& MARKETING



Daniella Conley
COMMUNICATIONS
MANAGER



Mikaela Manna
CLINICAL RESEARCH
UPDATES COORDINATOR

As CCRAN approaches its second year of incorporation as a not-for-profit national colorectal cancer patient advocacy organization, we believe we have finally turned the corner! We will move forward to launch additional initiatives and continue to support and inform our patients and caregivers in an evidence-based manner. It is also our hope that we will be able to eventually step out into the community to stage colorectal cancer awareness events.

Most new organizations face a myriad of challenges, and the uncertainty caused by the Covid-19 pandemic and the delay in obtaining official charitable status have been additional barriers that would have caused many new organizations to fail. There is no secret as to why CCRAN is a huge success story – it is entirely due to our very special members, supporters, and persevering patient population. We are unique because we honestly believe that the work we do every day is a labour of love and genuinely appreciated by all. **WE ARE CCRAN**.

## CCRAN Now Has Charitable Status

# CHARITABLE REGISTRATION NUMBER: 776821936RR0001



As of March 17, 2021, CCRAN has been issued charitable status and is now a nationally recognized and registered charity, which allows us the privilege of issuing tax receipts for every kind and generous donation made in excess of \$20.00.

CCRAN is overjoyed to have learned of its new status for it will permit us to move forward with our fundraising objectives to help sustain us throughout this unprecedented time as we continue to support, educate and advocate ('SEA') on behalf of colorectal cancer patients and caregivers. We hope we can continue to rely on your support as we now move into the next phase of CCRAN's growth.

## November 2020 Direct Mail Campaign Results

## CCRAN Asked and You Gave! Over \$15,000 Raised!



Bill and Kim McGinley

Patients, caregivers, and others touched by colorectal cancer responded to Bill McGinley's message and showed their appreciation and support for the marvelous work that CCRAN has done on their behalf.

CCRAN did not have charitable status at the time and could not issue tax receipts yet, so many donated generously and provided the much necessary funding to help us start the new year.

CCRAN is extremely appreciative of your kind and generous support during these difficult times and will continue to be there for you when you need us the most. Together, anything is possible.

#### **CCRAN'S SOCIAL MEDIA**

Our social media is up and running! CCRAN now has a presence on Facebook, Instagram, and LinkedIn! We are quite excited and invite you all to visit, follow, comment, and share our posts which we believe are relevant to the colorectal cancer community. Click on the icons to view our pages.







## March: Colorectal Cancer Awareness Month

For Colorectal Cancer Awareness Month, we determined that the patients and caregivers we support would be the best spokespeople to help create public awareness of colorectal cancer and to let everyone know how CCRAN plays such an important role in their daily lives. The following initiatives clearly demonstrated how our membership participated so enthusiastically in helping us deliver the message to *Screen it! Treat it!* Beat it!

## "I AM CCRAN" Campaign



Patients, caregivers, survivors, and supporters of CCRAN were asked to provide videos and photos of them holding the "I AM CCRAN" poster in order to show the different faces of who we support and how implicated they are in the organization.

A colorectal cancer journey is never easy. From diagnosis to treatment to recovery, those affected show incredible strength in the face of what can often be a scary journey, as they battle the unknown.

CCRAN is honored to have been alongside our heroes each step of the way, offering a shoulder to lean on and resources to learn from.

We are so thankful for every single survivor, patient, caregiver, and supporter who comprise our community. Together, anything is possible. Together, we are CCRAN.

Click here to view the "I am CCRAN" video.

## **CCRAN'S Patient Education Session**

Thank you to those who participated in CCRAN's Patient Education Session on March 21st, 2021. CCRAN was delighted to have featured four highly renowned experts who delivered thought-provoking and evidence-based information in the management of metastatic colorectal cancer. We are pleased to share their presentations with you.

This session was the first of two educational sessions in the fight against metastatic colorectal cancer. Please stay tuned as we schedule the second session for <u>August 15</u>, <u>2021</u>, which will focus on topics dedicated to the treatment of peritoneal disease, treatment-induced side effects, updates on the Hepatic Arterial Infusion Pump Chemotherapy and so much more.



Dr. Stephanie Snow Medical Oncologist QEII, Halifax, Nova Scotia



Dr. Gonzalo Sapisochin Liver Surgical Oncologist UHN, Toronto, Ontario



Dr. Marcelo Cypel Lung Surgical Oncologist UHN, Toronto, Ontario



Ms. Shaniah Leduc, RN
Director, Business Development
OncoHelix (CGP)

#### **Presentation Slides May be Accessed:**

Dr. Stephanie Snow:

<u>The Medical Management of Metastatic Colorectal Cancer – What's New?</u>

Dr. Gonzalo Sapisochin:

<u>The Surgical Management of</u>

<u>Colorectal Liver Metastases – Look</u>

<u>How Far We've Come!</u>

Dr. Marcelo Cypel:

<u>The Surgical Management of</u>

<u>Colorectal Lung Metastases – Can We</u>

Continue to Push the Boundaries?

Ms. Shaniah Leduc, RN:

<u>The Importance of Comprehensive</u>

<u>Genomic Profiling in the</u>

<u>Management of Metastatic</u>

<u>Colorectal Cancer</u>

#### THE FACES OF EARLY AGE ONSET COLORECTAL CANCER IN CANADA

**Did you know?** Colorectal cancer rates are on the rise in people under the age of 50 in Canada. It's an alarming trend.

**Click here** to hear about the inspirational journeys of young adult patients diagnosed with the disease across Canada determined to beat the odds.



Marie Taurasi, colorectal cancer survivor

## My Colorectal Cancer Consultant

My Colorectal Cancer Consultant is an online tool designed by CCRAN to provide patients with metastatic colorectal cancer with information about potential treatment options they can thoughtfully discuss with their treating oncologist. Patients will be guided through a series of questions requiring their pathology report. At the end, they will receive a personalized report that outlines the potential treatment options that may be appropriate for them based on their individual diagnosis.

The goal is to help patients have a thoughtful discussion with their treating oncologist by providing them with more evidence-based information on the potential treatment options that may be available for them and to encourage informed and joint decision-making between the patient and their treating oncologist.

Stay tuned, as this content will be up and running on the CCRAN website and available on smart phones very soon.





The Coulson family

## **Patient Testimonials**

We at CCRAN are in the privileged position to support, educate, and advocate for patients and their caregivers as they undergo their colorectal cancer journey. We are, therefore, honored to share these inspirational testimonials provided by patients and caregivers. These are personal accounts shared by patients, survivors, and their loved ones. They provide personal perspectives on how they were assisted by CCRAN throughout the most difficult and vulnerable moments of their lives as they navigated the health care system, evidence-based obtained pertinent, information on the management of the disease as well as helped to reduce feelings of loneliness, anxiety distress.

<u>Click here</u> to read the stories of strength and perseverance that are the makings of everyday HEROES.

Thank you to our supporting sponsors!











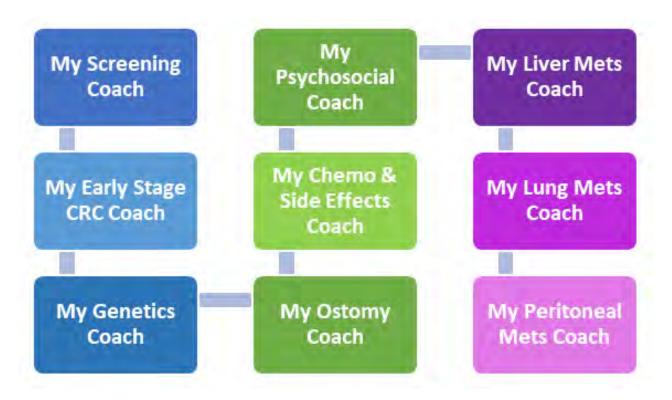




## **My Colorectal Cancer Coach**

My Colorectal Cancer Coach is a patient and caregiver support program wherein volunteers will receive annual mandatory training and certification across the continuum of colorectal cancer care. CCRAN's trained and certified Colorectal Cancer Coaches will guide patients through their screening, treatment, or survivorship journey, all to help them cope more effectively and assist them in making informed decisions regarding their care. Colorectal Cancer Coaches know how the medical system works since many have been through the same process and treatments themselves. Our Colorectal Cancer Coaches will provide one-on-one information and support.

One of the many benefits of CCRAN's Colorectal Cancer Coach Program is the opportunity to access a Coach whose expertise lies in an area which patient and caregivers may find important and is of relevance to their journey. For example, here are just some of the many Colorectal Cancer Coaches CCRAN will make available:



Please stay tuned, as this program will be officially up and running after our first My Colorectal Cancer Coach Conference in the winter of 2021.

Thank you to our supporting sponsors!





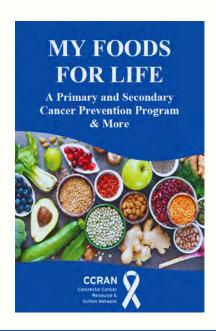
## My Foods For Life

Thanks to the American Institute for Cancer Research, CCRAN has proudly issued its **My Foods for Life** program: a primary and secondary cancer prevention program aimed at not only helping to prevent a cancer diagnosis but also helping to prevent a recurrence for patients who have been successfully treated for cancer. The program also goes above and beyond in so far as it furnishes patients who are actively undergoing treatment for their disease with goals of nutrition during their cancer therapies and common nutrition-related side effects of treatments, as well as strategies to help manage those treatment-induced toxicities.

The program and the booklet contain tasty, easy to prepare recipes to follow a nutritious and healthy diet to help prevent a cancer diagnosis or recurrence.

You can access the booklet or the entire program on the CCRAN website at: https://ccran.org/programs-advocacy/

Hardcopy versions are also available upon request. Please contact Frank Pitman at <a href="mailto:frank.p@ccran.org">frank.p@ccran.org</a>. We are happy to furnish you or your organization with <a href="mailto:free">free</a> copies.





#### Patient Advisory Council Members

Mr. Bill McGinley, Chair
Ms. Joy Coulson, Vice-Chair
Mr. Michael Calderone
Ms. Sandra Clementi
Ms. Sandra Elhilali
Mr. Robert Hamilton
Mr. Andrew Hare
Mr. John Kutkevicius
Ms. Armina Ligaya
Ms. Robin McGee
Mr. Frank Pitman
Mr. Martin Tayares

### Young Adult Patient Advisory Council Members

Mr. Andrew Hare, Chair
Ms. Ana Bettencourt
Ms. Franca Christodoulou
Ms. Christina Halladay
Ms. Andrea Jamieson
Mr. Amrit Kooner
Ms. Armina Ligaya
Ms. Marie Taurasi
Mr. Martin Tavares

#### **DONATE TO CCRAN:**

Online: www.ccran.org/donate

## **CCRAN's Position on** Colorectal Cancer **Patients Accessing the COVID-19 Vaccine**

undergoing Colorectal Cancer patients treatment may, theoretically, experience a diminished immune response to the COVID-19 vaccine due to their cancer therapy. However, significant experience with other vaccines suggests that COVID-19 vaccines will still be critical in reducing the risk of COVID-19 in patients with cancer.

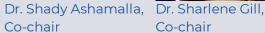
If you have been identified as eligible for the vaccine based on the provincial prioritization and you are on active cancer treatment or are that vou mav immunocompromised, please discuss this with your oncologist before receiving the vaccine.

Your Provincial Government's prioritization framework outlines the eligibility criteria and timelines for COVID-19 vaccination and may be accessed here bv enterina province/territory.



## Medical & Scientific **Advisory Board**







Co-chair

Dr. Eric Chen Dr. William Chu Mary De Vera, PhD Dr. Sam Elfassy Dr. Mary Jane Esplen Dr. Paul Karanicolas Dr. Yoo-Joung (Yooj) Ko Dr. Calvin Law Dr. Christopher Lieu Dr. Howard Lim Dr. Christine Brezden-Masley Stephanie Michaud, PhD Dr. Eric Marsden Dr. Michael Raphael Rachel Reed Dawn P. Richards, PhD Dr. Gonzalo Sapisochin Dr. Daniel Schiller Dr. Lucas Sideris Dr. Stephanie Snow Dr. Patricia Tang Dr. Mark Vincent Dr. Rebecca K S Wong Dr. Clarence Wong Dr. George Zogopoulos

### **CCRAN's HTA Submissions**

# Thank You to Clinicians and Patients for Providing Input into CCRAN'S HTA Submissions

CCRAN is both humbled and proud to have made three colorectal cancer patient input submissions to the expert committees in Canada who are overseeing the funding review of the following cancer drugs:

- VITRAKVI® (Larotrectinib) For the treatment of adult and pediatric patients with solid tumours that: have a neurotrophic tyrosine receptor kinase (NTRK) gene fusion without a known acquired resistance mutation; are metastatic or where surgical resection is likely to result in severe morbidity, and; have no satisfactory treatment options.
- KEYTRUDA® (Pembrolizumab) For the first line treatment of adult patients with unresectable or metastatic microsatellite instability-high (MSI-H) or mismatch repair deficient (dMMR) colorectal cancer (CRC) .
- BRAFTOVI® (Encorafenib) in combination with Cetuximab for the treatment of patients with metastatic colorectal cancer (mCRC) with a BRAF V600E mutation.

Additionally, CCRAN also coordinated a thyroid clinician input submission for VITRAKVI® and a colorectal cancer clinician submission for BRAFTOVI® input Cetuximab. Providing thoughtful compelling patient and caregiver input when cancer drugs come under a funding review is part of CCRAN's mandate to ensuring patients have access to effective therapies. CCRAN is grateful to the patients and caregivers who contributed to the submissions: to those who completed the online surveys, or participated in the focus

groups, or participated in the lengthy telephone interviews - A HEARTFELT THANK YOU TO YOU ALL! We could not done it without vou. contribution made all the difference in the world. Capturing your experiences with respect to the disease, current therapies and of course the drug under review will undeniably prove helpful in providing the expert committees with the valuable preferences patient values. and perspectives required to assist them throughout their deliberations.

A special vote of thanks to the clinicians, who work tirelessly every day to help our patients, for taking time out of their extremely busy schedules during this challenging and unprecedented time to lead the clinician input submissions. CCRAN is indebted to each of them for speaking on behalf of patients and caregivers across Canada through these input submissions. They were a unified, collective and compelling voice speaking on behalf of our patients in need of additional therapeutics for which they all thoughtfully and meticulously provided input. Patients and caregivers are most grateful for their efforts.

Please stay tuned as the expert committees (CADTH and INESSS) issue their funding recommendations very soon. We will surely keep you posted on their decisions.





## Early Age Onset Colorectal Cancer Virtual Symposium

In light of the rising rates of early age onset colorectal cancer in Canada, CCRAN decided to strategize a response to these rising rates by scheduling an inaugural symposium on June 17, 2021 with a clear focus on the young adult colorectal cancer population in Canada.

This will be the first of three symposia dedicated to this important topic, targeting primary care physicians as our primary audience at the first symposium, in addition to patients, individuals/organizations from the cancer care community, other health care professionals, researchers, academia, and policy makers. CCRAN has secured both Canadian and US experts to speak.

Following are the symposium objectives:

- To strategize a response to the rise in early age onset colorectal cancer in Canada.
- To "set the stage" and educate on the issues related to colorectal cancer in people under 50.
- To influence practice change amongst primary care physicians to support early diagnosis.

Please join us as our highly renowned experts address the disturbing rising rates in young adult colorectal cancer in Canada. Let us come together to work collaboratively to help reverse this alarming trend for young Canadians. You can register by <u>clicking here</u>.

### Thank you to our supporting sponsors!















## 10th annual Bumrun

On Sunday, April 25th, 2021, the 10th annual Bumrun was held in support of colorectal cancer awareness and prevention – and thanks to you, it was a great success!

Bumrun is a charity organization founded by Dr. Ian Bookman, a gastroenterologist in Toronto. Dr. Bookman founded the Bumrun to raise awareness and promote early screenings for colorectal cancer.

CCRAN is very excited to have partnered with Bumrun this year and going forward.

For the first time ever, Bumrun expanded across Canada, hosting the virtual run/walk event in Vancouver, Edmonton, Winnipeg, Toronto, Ottawa, and Halifax.

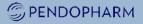
Participants around the country walked or ran their 5K any time up to and including April 25th, tracking their time and distance on their own. Beyond completing their 5K, many of our participants proved extraordinary in their fundraising efforts! This year, Bumrun surpassed it's goal and raised over \$115,000.

We are incredibly grateful for every participant, fundraiser, and donor – it is because of you that the 2021 Bumrun was such a success. CCRAN will judiciously utilize our funds to better support, educate, and advocate on behalf of patients and caregivers across Canada, We will work tirelessly to be worthy of every cent you worked so very hard to raise for CCRAN!

Thank you for your support and fundraising efforts. We can't wait to see you again in 2022!



#### Thank you to Bumrun's supporting sponsors!



































Fax: 905 303 2698 Toll Free: 1 833 79 CCRAN (22726) 905 417 0726 CCRAN.ORG

Email: info@ccran.org