WINTER 2022

CCRAN Colorectal Cancer Resource & Action Network
RISCC Réseau d'informations et soutien pour le cancer colorectal

VOL. 04

A PATIENT-FOCUSED ORGANIZATION

A Message from the CCRAN Team

A new year is upon us, and we at CCRAN are ready to work harder than ever in 2022 to continue to champion the health and wellbeing of Canadians touched by colorectal cancer!

Our team's hope for 2022 is to continue to expand upon CCRAN's mandate and vision, taking our support of patients and caregivers across Canada to new levels.

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There is much to look forward to from CCRAN this year. The **My Colorectal Cancer Coach Training and Certification Program**, the **11th annual Bumrun**, the second **Early Age Onset Colorectal Cancer Symposium,** and the **Young Adult Colorectal Cancer Hub** are just a few of the initiatives planned for this year.

Based on the feedback we've received and the overwhelming number of patients requesting support, CCRAN's online support group services will soon be stratified and delivered according to the following parameters:

- **Under 50 years of age** vs **over 50 years of age**
- **Early stage disease** vs **later stage disease**

Four National Colorectal Cancer Information/Support Groups will be hosted and offered to our patients and caregivers once training and certification is completed in June of 2022. Groups should be up and running shortly thereafter. CCRAN is excited to be offering this patient-focused approach to support and looks forward to serving patient needs according to patients' particular disease characteristics and social settings. Stay tuned, my friends!

Our team is more eager and determined than ever to serve our patient population, and we look forward to what the new year will bring! **Together, anything is possible!**

Filomena Servidio-Italiano
PRESIDENT & CEO

Grace Malito
MANAGER, ADMINISTRATION & MARKETING

Cathie Jackson
MANAGER, DEVELOPMENT

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MANAGER, COMMUNICATIONS & SPECIAL INITIATIVES

Sheila Verhage-Brown, MD
NATIONAL PATIENT PROGRAMS COORDINATOR

Mikaela Manna
CLINICAL RESEARCH UPDATES COORDINATOR

Morgan Kennedy
KNOWLEDGE TRANSLATION SPECIALIST

Manal Ghamlouche: Another Young Patient Determined to Beat The Odds

Back in 2015, giving birth to my child and being a busy mom, I ignored some very basic symptoms of colon cancer such as cramps, stomach pains, constant bloating etc. But then again, many people complain from this all the time, so I didn't think much of it. Years before all of this, I had a constant decline in my iron levels to the point where it became dangerously low, and I needed to be in the hospital to get transfusions in order to keep my iron levels up.

My doctor initially kept blaming it on not enough iron in my diet, telling me to eat more spinach, for example, and also blamed it on my menstrual cycle. However, when I look back now on my blood work, my iron was completely off, and I am really surprised this was not investigated further, but I had 100% trust in the doctors and the system. But I was a young patient, and this likely accounted for the attitude. Not one doctor investigated the source of my very low iron, and all I was given were short term remedies rather than the true root cause for the low iron levels. So taking iron pills up to 3 pills a day for years and years, I was unable to see any blood in my stool.

In 2018, when my son was 3 years of age, I saw drops of blood in my stool and I knew something was wrong but I dismissed it until I

> **Going to those support group meetings and getting reassurance and advice from [Filomena] (obviously on top of my oncologist) was invaluable and helped me understand my disease better and deal with my fears and feelings.**

saw more blood, and that is when I went to the emergency one day. That day was when I was told I had cancer after they did a CT scan to identify the root cause. I ended up getting my surgery and my treatment for stage 3 colon cancer at North York General Hospital. My fears of this disease and having a young child was challenging. I desperately wanted to reach out to someone or some support group to help me get through this. As much as I can say my family was supportive, I needed to talk to people who knew my disease and were going through what I was going through. I remember being referred to Filomena's group, and this is when our relationship started. She was amazing, accommodating and from the beginning made me feel so comfortable, welcome and at ease. Going to those support group meetings and getting reassurance and advice from her (obviously on top of my oncologist) was invaluable and helped me understand my disease better and deal with my fears and feelings.

I want everyone who reads this and is diagnosed with colorectal cancer or knows someone who is diagnosed with colorectal cancer to know that there is help out there, there is hope and there are people you can talk to about your journey. I am 3 years out from my disease now, being monitored and feeling better and optimistic that one day I can put this behind me. Please know that you are not alone. Together, we can do this.

Manal Ghamlouche
Stage III Survivor

CCRAN's Information and Support Group

CCRAN was formed from a single information/support group in August 2006 and has been the largest and longest running colorectal cancer information/support group in Canada. Its success is entirely based on its delivery of evidence-based information on the management and prevention of the disease as well as caring interactions from peer-to-peer psychosocial support.

Please join CCRAN for a patient/caregiver support group meeting and:

- 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
- All stage-patients and their caregivers are welcome

The virtual 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

Please RSVP before each meeting to Sheila Verhage-Brown at sheila.v@ccran.org.

My Colorectal Cancer Consultant Part I

Are You a Newly-Diagnosed Advanced Colorectal Cancer Patient? Then Check Out CCRAN's *My Colorectal Cancer Consultant* Tool!

My Colorectal Cancer Consultant is an **online tool** designed by CCRAN to provide patients with **advanced colorectal cancer** with information about potential treatment options that they can 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 information in this online tool is based on **evidence and clinical practice guidelines.** The **four highly renowned medical experts** 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.

The goal is **to help patients have a thoughtful discussion with their treating oncologist** by providing them with 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.

Check out the *My Colorectal Cancer Consultant* online tool at ccran.org/consultantprogram/.

Dr. Shady Ashamalla
Colorectal Surgical Oncology

Dr. Christine Brezden-Masley
Medical Oncology

Dr. Paul J. Karanicolas
Hepatobiliary Surgical Oncology/HAIP Chemotherapy

Dr. Rebecca K.S. Wong
Radiation Oncology

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My Colorectal Cancer Consultant Part II

Coming Soon!

My Colorectal Cancer Consultant Part II focuses on **Colorectal Cancer Drug-Induced Side Effects.** Patients who will be undergoing or 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 life.

To assist the online user with the management of treatment-induced side effects, **a list of side effects** is being developed and can be accessed alphabetically. The online tool will also provide links to drug side effect monographs for each colorectal cancer drug. These are intended to assist patients in understanding the toxicity profile of a particular drug. The tool will also furnish the side effect's cause and potential remedy.

Recognizing the early signs of a drug induced toxicity is critical in helping to avoid an emergency department visit, a hospital admission, a dose reduction or, potentially, a treatment cessation.

When accessing a particular drug-induced side effect, the user will be presented with the following information for each respective side effect:

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

Images will also be provided where applicable to assist with the understanding of the content delivered.

By creating an online compendium, patients will have a resource whose quality and calibre of information they can trust. Dr. Eric Chen, Dr. Stephanie Snow, Dr. Michael Raphael, and Dr. Jennifer Spratlin – four highly renowned medical oncologists – have graciously agreed to serve as the four consultants for part II of the program.

Dr. Eric Chen
GI Medical Oncology

Dr. Michael Raphael
GI Medical Oncology

Dr. Stephanie Snow
Medical Oncology

Dr. Jennifer Spratlin
Medical Oncology

Accessing My Colorectal Cancer Consultant Part II may promote open and thoughtful communication between the patient and their treating oncologist, encouraging the patient to share any early signs of treatment-induced adverse events. This encourages a shared decision-making process, one wherein the patient is actively participating alongside the clinician.

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Colorectal Cancer Awareness Month

March is Colorectal Cancer Awareness Month, and our team is working hard to prepare CCRAN's awareness campaign for the month!

Colorectal cancer is the third most commonly diagnosed cancer in Canada, and CCRAN is dedicated to raising awareness, encouraging screening, and educating the population on colorectal cancer prevention – during Colorectal Cancer Awareness Month and beyond!

Stay tuned for important awareness initiatives, messages from CCRAN ambassadors, our upcoming patient education session scheduled for March 20th, and our call to action to promote awareness of colorectal cancer in Canada!

CCRAN's Social Media

CCRAN is active on Facebook, Twitter, Instagram, LinkedIn, and, newly, 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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Heroes' Headquarters

Last fall, CCRAN introduced its new forum entitled Heroes' Headquarters, which features inspiring stories of the tireless and valiant work being done every day by our colorectal cancer oncologists to improve the lives of our patients as they navigate through what can often feel like the impossible colorectal cancer journey.

In Heroes' Headquarters, we are sharing inspirational stories about the special bond between the treating oncologist and their patient and how that special relationship affects the patient's quality of life and plays an important role in the patient's outcomes. Each episode highlights the extraordinary and compassionate work of our clinicians and the bravery and perseverance of our colorectal cancer patients.

The intention behind sharing these stories is to provide renewed encouragement, hope, and inspiration for patients and caregivers as they undergo their own journey.

The first video series features three leading clinicians and their patients, who are members of CCRAN:

- **Dr. Michael Raphael**, Medical Oncologist, Odette Cancer Centre and **Ms. Ana Bettencourt**
- **Dr. Sharlene Gill**, Staff Medical Oncologist at the BC Cancer Agency and **Mary De Vera, PhD**
- **Dr. Gonzalo Sapisochin**, Hepatobiliary Surgical Oncologist UHN, Toronto and **Ms. Sandra Elhilali**

Check out episodes one to three at ccran.org/heroes-headquarters/. In the coming months, you can expect to see additional series of Heroes' Headquarters posted, so stay tuned!

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Anna De Ferrari's Journey

CCRAN is delighted to share the story of Anna De Ferrari's journey and her hopes for CCRAN.

Anna De Ferrari

In October 2021, Anna was diagnosed with advanced ovarian cancer. The diagnosis came as a shock, as Anna led a very healthy lifestyle. Scans were scheduled well into the new year and referrals to specialists thereafter, but Anna was feeling less and less well with each passing day.

Anna and her family made the decision to contact CCRAN. Anna was immediately referred to Dr. Bernardini, the highly renowned divisional head of gynecology oncology at the Princess Margaret Cancer Centre.

Two weeks after diagnosis, Anna, her family, and CCRAN had already met with Dr. Bernardini and received the necessary scans and tests. Soon after, Anna received the life-saving 12-hour surgery she so desperately required.

In appreciation of all that CCRAN has done, Anna and her family started a GoFundMe fundraiser for CCRAN, hoping to raise $50,000 to help expand CCRAN's patient programs so that many more families will be assisted and provided with support and guidance.

Anna's hope is for these donations to help CCRAN grow and flourish so that we can continue to support many more families with the same love, guidance, and care.

The De Ferrari family raised $51,000 for CCRAN, for which we are truly grateful. Appearing below is a message from Anna's daughter, Kellie:

We are proud to have hosted and led this online fundraiser for CCRAN. We do not know where our mom/wife/grandmother would be today were it not for CCRAN, who has been there every day since the beginning with referrals, interpreting results, participating in consults, helping make sense of complicated information, delivery of presentations to family, and so much more. There really is no other patient group like them, and we were so lucky to find them. They need to grow so that other families can be supported like we have been. It made the world of difference for my mom. Please support CCRAN. You never know when someone you love will end up needing their help for the fight of their life.

Kellie Crupi

Early Age Onset Colorectal Cancer Hub

Coming Soon!

CCRAN's Early Age Onset Colorectal Cancer (EAOCRC) Hub is on its way!

The Hub is aimed at supporting the **under 50 patient population.** Colorectal cancer has historically been considered a disease that primarily affects people over the age of 50. This belief has allowed the early age onset population to be under-served.

CCRAN is working to address this inequity by creating a Hub of resources for early age onset colorectal cancer patients.

The Hub will include a vast array of educational materials regarding colorectal cancer, the different stages, treatment options, and more.

All of the information from CCRAN's EAOCRC virtual symposium, held in June 2021, will also be available, including links to each expert presentation.

The Hub will feature testimonials from many of CCRAN's early age onset patients, which will surely inspire hope and courage in other newly-diagnosed young patients.

As the Hub has been created in partnership with Sunnybrook Health Sciences, it will also feature resources and access to their **Young Adult Colorectal Cancer Clinic.**

Most interesting of all, the Hub will feature a live chat option, which will be moderated by both **Sheila Verhage-Brown MD, CCRAN's National Patient Programs Coordinator**, and **Dr. Petra Wildgoose, Primary Care Physician Lead at Sunnybrook's Young Adult Colorectal Cancer Clinic.** The live chat will allow patients the opportunity to submit questions to experts across the continuum of colorectal cancer care.

Stay tuned for more information and the exciting launch of the Hub!

NEW PUBLICATION

CURRENT ONCOLOGY

PRACTICE GUIDELINE

A catalyst for transforming health systems and person-centred care: Canadian national position statement on patient-reported outcomes

ABSTRACT

BACKGROUND AND CONTEXT

CCRAN is delighted to have participated and been included in the following publication, *A catalyst for transforming health systems and person-centred care: Canadian national position statement on patient-reported outcomes.*

The article highlights the use of patient-reported outcomes to create a more patient-centred health care system. This is the first of many more publications expected from CCRAN in 2022.

The collective authorship includes: S. Ahmed, L. Barbera MD, S.J. Bartlett PhD, D.G. Bebb BMBCh PhD, M. Brundage MD, S. Bryan PhD, W.Y. Cheung MD MPH, N. Coburn MD MPH, T. Crump PhD, L. Cuthbertson BHSc(OT) MEd PMP, D. Howell RN PhD, A.F. Klassen BA DPhil(Oxon), S. Leduc RN, M. Li MD PHD, N.E. Mayo BSc(PT) MSc PhD, G. McKinnon MD, R. Olson MD MSc, J. Pink PhD RPsych, J.W. Robinson PhD RPsych, M.J. Santana MPharm PhD, R. Sawatzky PhD RN, R.S. Moxam MSc, S. Sinclair PhD, F. Servidio-Italiano HonBSc BEd MA, and W. Temple MD

My Colorectal Cancer Coach Training and Certification Program

CCRAN is excited to be holding it's My Colorectal Cancer Coach Conference in Summer 2022!

This two-day training and certification program will deliver content acumen by our colorectal cancer experts, who will train our Colorectal Cancer Coaches so they can assume a level of expertise in the management of colorectal cancer and in the delivery of support services to patients diagnosed with colorectal cancer.

Once CCRAN's patient and family Colorectal Cancer Coaches are trained and certified, they 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 disease. Colorectal Cancer Coaches know how the medical system works since many have been through the same process and treatments themselves. They will be able to support and answer questions from patients and caregivers alike.

One of the many benefits of CCRAN's My Colorectal Cancer Coach Program is the opportunity to access a Coach whose expertise lies in an area which patients 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:

Highly trained colorectal cancer coaches will also help patients navigate the health care system when it comes to treatments. They can also assist patients when it comes to specific topics across the continuum of colorectal cancer care because they have lived the experience and received special training and certification. Overall, a colorectal cancer coach can help patients manage their care,

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Bumrun 2022

Get Your Butts in Gear!

It's 2022, and we're gearing up for this year's Bumrun 5K! This year's Bumrun event will be taking place on **Sunday, April 24, 2022** (and Sunday, May 1, 2022 in Calgary).

Bumrun's mission is to increase awareness of how common colorectal cancer is today; to increase participation in screening programs to prevent colorectal cancer; and to raise funds for charities that have a record in saving lives through promoting easy access to screening.

We are very excited to announce that the virtual Bumrun event will be taking place in six cities across Canada this year: **Vancouver, Calgary, Edmonton, Toronto, Ottawa, and Halifax!**

Furthermore, we are thrilled that the Bumrun will be going **live in Toronto and Calgary, barring any public health restrictions**. Vaccination against COVID-19 is mandatory, and all COVID-19 protocols must be followed. We must prioritize the health and safety of our runners and volunteers.

Learn more about this year's event and register in a city near you at www.bumrun.com to promote life-saving screening and much needed funding for CCRAN!

bumrun

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CCRAN's Updated Mandate

CCRAN Is Expanding Its Mandate to Serve a Wider Patient Population Through Patient Evidence Submissions

CCRAN is pleased to expand its patient-focused mandate to serve a population of patients with cancer outside of or unrelated to the colorectum through drug therapy review submissions.

CCRAN's new direction involves preparing Patient Evidence Input Submissions for oncology drugs related to other pathologies besides colorectal cancer on behalf of third-party organizations. These drug therapy submissions will be reviewed by the pan-Canadian Oncology Drug Review (pCODR) Expert Review Committee (pERC) at the Canadian Agency for Drugs & Technologies in Health (CADTH) and by L'Institut National D'Excellence en Santé et en Services Sociaux (INESSS) for the patients' valuable perspectives, values, priorities, and preferences in respect of the therapy under review, as well as capturing the patients' experience with respect to the disease journey and any previously administered treatment-induced toxicities.

By working to expand access to different oncology drugs, CCRAN hopes to positively impact the lives of multiple tumour type patients across Canada, including colorectal cancer patients. Though the drugs being reviewed may not initially be intended for use by colorectal cancer patients, the availability of these drugs will indirectly benefit the colorectal cancer patient population through multiple indications and funding approvals. Broadening the accessibility of drug therapies will benefit the Canadian population by ensuring additional treatments are available for patients who require them.

CRAN would be pleased to assist with HTA patient and clinician evidence input submissions within the oncology space for:

i. patient groups who do not have the capacity to perform these submissions

ii. a drug therapy wherein there currently is no representative patient group

CCRAN will work tirelessly to advocate on behalf of all Canadians for public funding and access to oncology drug therapies.

In addition to the many colorectal cancer submissions made, CCRAN (or its consulting company, Blue Ribbon Project) has made submissions for the following tumour types:

- breast (patient submission)
- chronic immune thrombocytopenia (clinician submission)
- thyroid (clinician submission)
- GIST (clinician and patient submission)
- endometrial (patient submission)

CCRAN looks forward to making many more submissions!

The Colorectal Cancer Project

CCRAN is excited to be involved as an advocacy partner for the Colorectal Cancer Project by Count Me In. **Over 180 people from across Canada & the US have already said "Count Me In."**

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 colorectalcancerproject.org.

The locations of over 180 patients who have thus far participated in The Colorectal Cancer Project.

CCRAN
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