

A PATIENT-FOCUSED ORGANIZATION

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Greeting from The CCRAN Team



Though summer may be winding down for some, we only know one pace here at CCRAN: full steam ahead!

Throughout the past months, CCRAN has been busy developing resources such as **My Colorectal Cancer Consultant**, preparing for new initiatives such as the **Silent Auction to Silence Cancer**, and educating through programs such as the **Patient Education Sessions**.

Plus, our team has grown! CCRAN is delighted to announce that we have now acquired two new team members: **Ms. Cathie Jackson** and **Ms. Morgan Kennedy**.

Cathie joins CCRAN as the Manager, Development. She has extensive experience working with non-profit health organizations. Her warmth and expertise will be a wonderful asset in guiding CCRAN's development and direction.

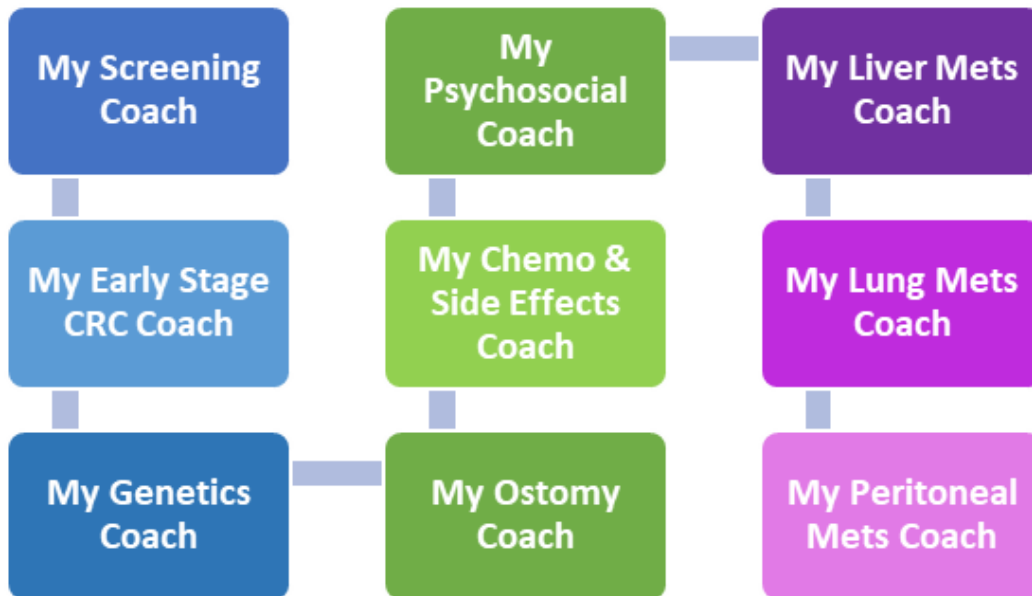
Morgan joins CCRAN as the Knowledge Translation Specialist. She is a good friend to CCRAN and brings a wealth of experience from the health charity sector. She is motivated and inspired to do good work to benefit the colorectal cancer population.

Welcome, Cathie and Morgan! We can't wait to see how CCRAN grows from here!

My Colorectal Cancer Coach

CCRAN's trained and certified patient and family Colorectal Cancer Coaches guide you through your screening, treatment, or survivorship journey, all to help you cope more effectively and assist you in making informed decisions regarding your disease. Colorectal Cancer Coaches know how the medical system works since many have been through the same process and treatments themselves. We are there for you.

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 you may find important and is of relevance to your journey. For example, here are just some of the many Colorectal Cancer Coaches CCRAN will make available to you throughout your journey:



Getting screened for colorectal cancer or being newly diagnosed can be overwhelming. Our colorectal cancer coaches will help you make sense of your options and will follow up with you on your next steps.



Highly trained colorectal cancer coaches will also help you navigate the health care system when it comes to treatments. They can also assist you 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 you manage your care.

You can reach My Colorectal Cancer Coach by calling our toll-free information line at: **1 833 79 CCRAN (22726)** or email us at info@ccran.org. **Together, anything is possible!**
(PROGRAM LAUNCH DATE SET FOR JANUARY 2022)

Thank you to our supporting sponsors!



My Colorectal Cancer Consultant Part I

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 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.

The online tool is now in the pilot stage and will be available on your computer and smart phone very soon.

My Colorectal Cancer Consultant Part II

Part II of My Colorectal Cancer Consultant focuses on Colorectal Cancer Drug-Induced Side Effects. Patients who will be undergoing or are actively undergoing systemic 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.

To assist the online user with the management of treatment-induced side effects, a list of side effects will be developed and 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.

When accessing a particular drug-induced side effect, the user will be presented with the following information for each respective side effect: **(1) Description of the Side Effect; (2) Cause of the Side Effect; (3) Symptom(s) of the Side Effect; and (4) Remedy/Treatment.** Images will also be incorporated/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.

CCRAN believes this initiative to be of utmost importance in promoting much needed information to those who rely on the internet for evidence-based, reliable and accurate information in the management of advanced colorectal cancer.

Thank you to our supporting sponsors!



CCRAN'S Patient Education Session Part II

Thank you to those who participated in CCRAN's Patient Education Session on August 15th, 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 grateful for their time and expertise.

This session was the second of two educational sessions in the fight against metastatic colorectal cancer. Part II focused on the therapies that are treating metastatic colorectal cancer (mrc) such as HAIP, PIPAC, and HIPEC, as well as the role being played by ctDNA in the management of mrc and how to manage treatment-induced side effects!

The session recording is now available [here](#).



Dr. Paul Karanicolas
Liver Surgical Oncologist/
HAIP Program
Sunnybrook Health Sciences



Dr. Anand Govindarajan
Peritoneal Surface Malignancy
Surgical Oncologist
Mt. Sinai Hospital



Dr. Michael Raphael
GI Medical Oncologist
Odette Cancer Centre
Sunnybrook Health Sciences



Dr. Barry Elkind, PhD
Senior Director,
Business Development.
Canexia Health, Toronto, Ontario



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New Board Member

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. CCRAN is privileged to be governed by an esteemed group of professional men and women

CCRAN is delighted to announce that Ms. Stephanie Prizzi has joined our esteemed Board of Directors. She brings great value to our governing Board.

CCRAN's Silent Auction to Silence Cancer in Support of CCRAN's EAOCRC Hub

In response to the alarming rise in early age onset colorectal cancer (EAOCRC) in Canada, CCRAN will be hosting an online fundraising event entitled **Silent Auction to Silence Cancer** on **September 7, 2021**. It is designed to support CCRAN's newest initiative, the Young Adult Colorectal Cancer Hub, which is part of CCRAN's patient support program in partnership with Sunnybrook's Young Adult Colorectal Cancer Clinic.

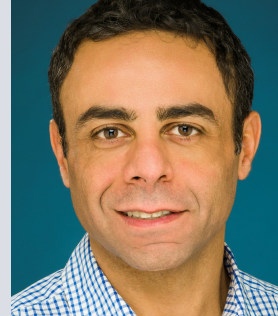
Participants will take their chances to bid on highly sought-after goods and services, while helping to raise awareness and funds for young adult CRC patient support and advocacy efforts.

CCRAN's Young Adult CRC Program aims to promote best practices in EAOCRC diagnosis and care, facilitating patient and expert collaboration through working groups, conferences, and the development of patient tools.

To that end, the hub will provide various resources to patients diagnosed with EAOCRC, such as information on the disease, information on Sunnybrook's Young Adult Colorectal Cancer Clinic, and access to an information and support chatroom moderated by CCRAN. The hub will also serve as a platform for sharing the brave stories of our young fighters to inspire and encourage others who are newly diagnosed.



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Heroes' Headquarters

Coming Fall 2021 to the CCRAN Website and Social Media

CCRAN's Heroes' Headquarters pays tribute to the tireless efforts of our oncologists who have made a meaningful difference in the lives of our patients by providing them with the best available therapies, compassionate care, and ongoing hope throughout their cancer treatments. In Heroes' Headquarters, we are sharing inspirational and touching stories about the special bond created 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 outcome.

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 **Dr. Mary De Vera**
- **Dr. Gonzalo Sapisochin**, Hepatobiliary Surgical Oncologist UHN, Toronto and **Ms. Sandra Elhilali**

This video series will surely offer hope, inspiration, and encouragement to patients undergoing the journey by showcasing the compassionate, heroic, and relentless efforts of CCRAN's clinician champions.



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Announcing CCRAN's Strategic Partnership with iMD Health Global

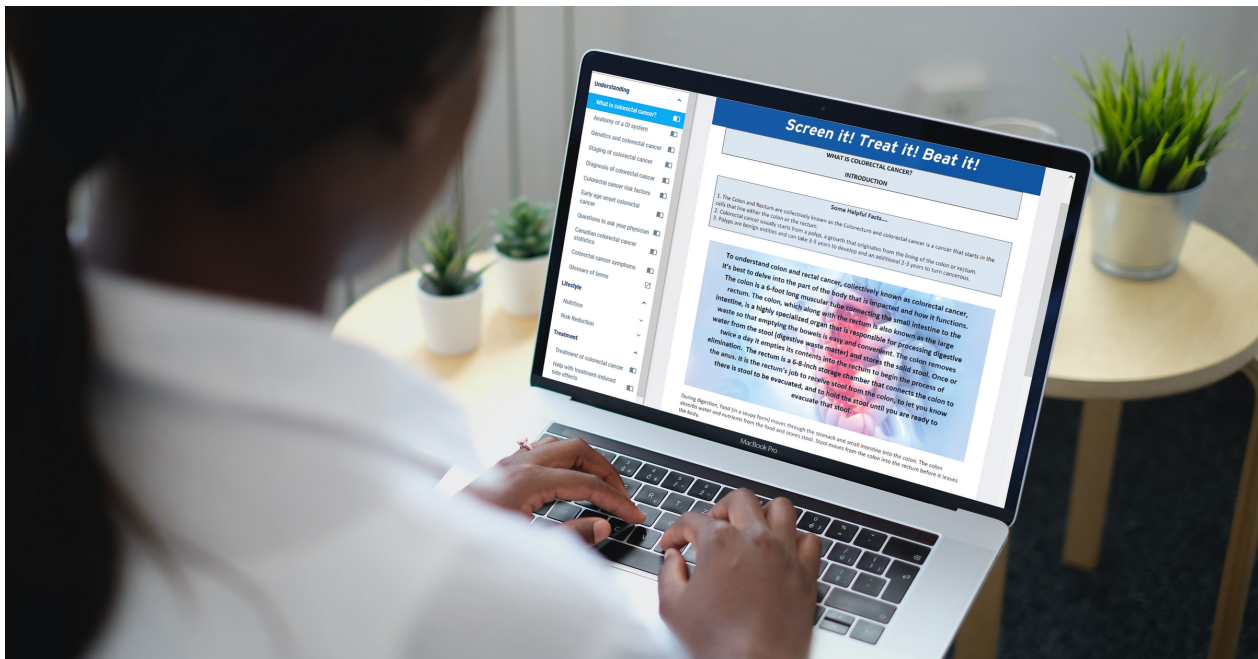
CCRAN is pleased to announce an important partnership with iMD Health Global (iMD), a CloudMD Software & Services company focused on health education, to provide credible colorectal cancer resources to healthcare providers and patients on the iMD platform. This partnership provides increased access to healthcare providers and patients wanting to not only better understand colorectal cancer but also prevention steps.

iMD Health is the largest digital health educational platform in Canada. iMD offers innovative technology that facilitates meaningful dialogue between healthcare professionals and patients inside the examination room, hospital bedsides, pharmacy consultations, and during virtual consultations. iMD's award winning platform enables healthcare professionals to instantly access over 110,000 educational graphics,

videos and resources at the point of care, across Canada.

"We are thrilled to collaborate with CCRAN in order to provide our healthcare providers and their patients with trusted colorectal cancer resources to improve engagement and understanding" said Jared Sonnenberg, Vice President of iMD, citing the need for accurate, reliable health information, particularly given the shift toward digital tools incited by the pandemic and the use of the internet which often leads to misinformation.

Through a resource like iMD, healthcare providers, patients, and families will gain a better understanding of colorectal cancer. CCRAN is thrilled to be expanding our educational outreach through this partnership! Check out our iMD Health Partner Folder [here](#).



CCRAN'S SOCIAL MEDIA

Stay up to date no matter where you are! CCRAN is on Facebook, Instagram, Twitter, and LinkedIn! We 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.



Update to CCRAN's HTA Submissions

Earlier this year, CCRAN was both humbled and proud to have made three colorectal cancer patient input submissions to the expert committees in Canada who oversaw 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.

CCRAN is pleased to announce that the funding recommendations have been made for KEYTRUDA® (Pembrolizumab) and BRAFTOVI® (Encorafenib).

The CADTH pCODR Expert Review Committee (pERC) has recommended that **BRAFTOVI® (Encorafenib)** in combination with Cetuximab be reimbursed for the treatment of patients with metastatic colorectal cancer (mCRC) with a BRAF V600E mutation, as detected by a validated test, after prior therapy, with some conditions. CCRAN is delighted with the recommendation! For a review of the draft recommendation, please see [here](#).

The CADTH pCODR Expert Review Committee (pERC) has also recommended that KEYTRUDA® (Pembrolizumab) be reimbursed as monotherapy for the first line treatment of metastatic microsatellite instability-high (MSI-H) or mismatch repair deficient (dMMR) colorectal cancer, with some conditions. CCRAN was very pleased with the decision on

behalf of its MSI-H/dMMR patient population. For a review of the draft recommendation, please see [here](#).

We await a final funding recommendation for **VITRAKVI® (Larotrectinib)**.

Providing thoughtful and 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 have done it without you. Your contribution made all the difference in the world.

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.





Early Age Onset Colorectal Cancer Virtual Symposium

On June 17, 2021, CCRAN hosted its Early Age Onset Colorectal Cancer Virtual Symposium.

This was the first of three complimentary symposia that CCRAN will be hosting in response to the growing number of patients diagnosed with colorectal cancer under the age of 50 years seeking support, education, and advocacy for advanced colorectal cancer. Over the course of these three symposia, CCRAN will educate on, strategize, and implement a response to the rise in early age onset colorectal cancer (EAO CRC) in Canada.

We were privileged to host an incredible panel of highly renowned expert speakers from across North America to discuss such topics as the importance of family history, the case for early detection, treatment pathways, and so much more.

In addition to these expert presentations, CCRAN held a Young Adult Patient Panel Discussion, facilitated by Dr. Dawn Richards, where we heard deeply impactful testimony from Andrew Hare, Ana Bettencourt, Armina Ligaya, and Bill McGinley on their own lived experiences with EAO CRC.

Throughout the symposium, our speakers underscored the significant impact EAO CRC has on the young adult population. CCRAN recognizes the profound importance of collaboratively addressing the rising rates in EAO CRC in Canada, and we are determined to help reverse the trend.

Thank you to our sponsors for having made this event possible and to our Steering Committee, chaired by Dr. Sharlene Gill and Dr. Shady Ashamalla, and panel of speakers for ensuring such a successful event. Stay tuned as we issue our meeting report and follow up with the scheduling of our 2022 symposium.

In the meantime, click [here](#) to view the symposium recordings; you can watch the entire symposium or view individual sessions.

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 frank.p@ccran.org. We are happy to furnish you or your organization with free copies.



**MY FOODS
FOR LIFE**

**A Primary and Secondary
Cancer Prevention Program
& More**

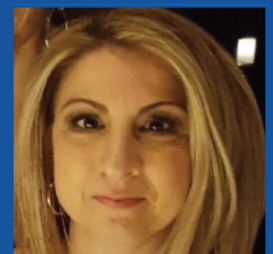
CCRAN
Colorectal Cancer
Resource &
Action Network



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

Sandra: Redefining the Metastatic Journey

Our journey with cancer started on the morning of Mother's Day, 2017. In truth, looking back, it started long before then. I had been feeling tired for a long time, but who wouldn't be? I was a mom to two young children. I had a demanding career, and we were a busy household. Eventually, it all became too much. I was working longer days and would come home exhausted. My family were getting less and less quality time with me. I would spend free time on the weekends catching up on chores and sleeping the rest of the time. Spending time with my husband and the kids outdoors biking, hiking, and skiing doing things that I loved was becoming infrequent and became nonexistent in late 2016.

The tiredness became insurmountable. It wasn't uncommon for me to fall asleep on my son's bed from sheer exhaustion of having just made it. I also had a recurring sharp pain on my right side that I dismissed as a pulled muscle. My family physician was stumped. My bloodwork was near perfect, with the one exception of low iron levels - all easily treatable. We didn't realize then that the symptoms I was experiencing were all warning signs. We had no reason to suspect Colon Cancer, as my FIT test came back clear. My physician confidently declared "you are the picture of health" and handed me a prescription for Iron tablets.

It wasn't until early May of 2017 that I found myself at our Walk-In-Clinic with my daughter. We were there for her sore throat. When the doctor was done assessing her, my 11-year-old suggested that I tell the doctor what was happening with me, and so I did. The doctor listened as I listed my symptoms. She looked over my recent labs and stated, "I am going to schedule you for the dreaded C word (colonoscopy) to rule out the other dreaded C word (Cancer)." I left her office relieved that my daughter would be fine and incredulous that she thought I needed a colonoscopy. What non-smoking, active 43-year-old needs a colonoscopy, I thought to myself.

I woke from what would be first of many colonoscopies to see a pained expression on my GI's face while asking if my husband was with me and to wait in his office so he could speak with us both. I thought to myself that he was being awfully formal for delivering the news that he found a bleeding ulcer, something that I had before. I was in disbelief



when he announced he had found a growth on my sigmoid, and there was a chance it was cancer. I was referred to a GI specialist, with an appointment for September; an appointment that I never made it to.

Bright and early on May 14th, I woke to the laughter of Jasmin & Eric as they leaped onto my bed, smothering me with hugs as they declared 'Happy Mother's Day!' followed by pleading with me to get ready for a day at our local park by the lake, as was our family tradition. I was busy packing our things for our picnic when my husband said, "You don't look well, you're shaking like a leaf and you're so pale. We should go to the hospital to be safe. I'm worried about you." I knew he was right.

After countless blood draws, followed by scans, I am sitting on the edge of the gurney in a hospital ER when I notice a group of people in white lab coats gathered around a light board to look at images, that I assume are x-rays. Some have their head tilted, while others scratch their head, I can only imagine that they are doctors and these images have them puzzled.

I grow increasingly uneasy as one turns back to look at me. The doctor who I had seen gathered with the others walks towards me and my husband with the images. Sharif and I reach for each other's hand as we hear the words that will forever change our lives - "I am so sorry to tell you that you have cancer."

Continued on page 12



I was in disbelief. Surely, they have this wrong. It wasn't until much later that evening, that a kind radiologist sat with me while we counted the tumors on my liver that now resembled a spotted dalmatian. We never did know how many there were exactly as we felt we didn't need to continue once we reached twenty. The CT radiology report simply read "there are too many to count."

I was admitted that evening and met with the Oncologist the next day, where we learned I was incurable, I had roughly 5 to 6 months, chemo would be palliative and I most likely would not be returning home. As devastating as the news was, I had a sense of relief in finally knowing what was wrong with me. Finally, we could get to the business of recovery. With that I began chemotherapy one day after being diagnosed.

I spent my days chatting with nurses and other cancer patients and my nights reading medical journals, trying to learn as much about my disease as possible. I focused on the probability of surviving Stage IV CRC, which was bleak. I wanted no part of the timeline I was given, so I shifted my attention to finding cases where stage IV cancer patients were not only outliving their timeline but thriving.

I had an incredibly positive response to chemotherapy, with a drastic drop in CEA to 824 from an initial skyrocketing number of 6082. Our highly regarded and cherished Oncologist was running a clinical trial for HAI pump chemo, a process where a hockey puck sized pump is implanted in the abdomen, delivering chemo directly to the liver. The hope was to reduce the volume of tumors on my liver, so that we could get to a liver resection. This was the first time we had discussed the removal of my primary tumor on my colon. In that moment I knew I wanted to take this gift of hope and pay it forward by raising awareness.

My Oncologist strongly suggested I reach out to Filomena at CCRAN. Little did I know just how much Filomena would forever change the trajectory of our family's life. I will never forget the first time I spoke with Filomena. I was still coming to terms with my diagnosis and was so uncertain of our future. Having done so much reading, I was left with more questions than answers. Filomena was reassuring, and she had

"Finding CCRAN was like finding my tribe, an empowered group of likeminded individuals looking for a clear path forward."

several questions of her own for me so that she could fully understand the gravity of our situation and how to best go about helping us. That first call with her was the beginning of a lifelong friendship and a profound appreciation for the work that she does through CCRAN.

A few months later in October, I received my Codman pump and learned that my primary tumor on my colon was all but gone, sparing me from an ostomy. While HAI did not get me to a liver resection, it did keep my cancer stable long enough to qualify me for a Living Donor Liver Transplant at UHN. I received my gift of life from our guardian angel, Jorge, on May 1st of 2019. I have been cautiously NED for two years now and my daughter has since started high school, with my son not far behind her.

When I first started considering Liver Transplant, I had a lot of hesitation and so many questions. What does life after transplant look like? Is it safe for our living donor? How do we go about finding our special donor? Thankfully, the Transplant team and our extraordinary Oncology Transplant Surgeon at Toronto General Hospital patiently addressed our concerns.

Liver transplants for mCRC had never been done before in Canada. I could possibly be the first, and that's when I connected with the very first and only Living Donor Liver Transplant recipient from mCRC in North America. Carol's journey was so remarkably like my own. She was an active, healthy young mother to two children, had undergone HAI, and finally received her gift of life in the spring of 2018. Carol's willingness to openly share her journey, gave me the confidence to move forward.

We often don't recognize how invaluable our personal stories are to others. They give us hope, when too often there is so little. Finding CCRAN was like finding my tribe, an empowered group of likeminded individuals looking for a clear path forward. I am forever grateful to Filomena for having the vision to create this safe place for us to voice our deepest fears and share our personal victories. I have gained so much knowledge from the research that Filomena brings to us. It is this shared knowledge that empowers us to advocate for ourselves. It is solely through her encouragement that I lend my voice to raising awareness of this disease. Her passion and dedication are both inspiring and infectious.

It is hard to believe that it has been four years since I was diagnosed. As I reflect on our journey that has been filled with obstacles, disappointments, and sadness, it has also brought us hope, special bonds of kinship that will never be broken. I will carry our dear friends who were called away far too soon in my heart. I will continue to raise awareness for as long as I possibly can, in honor of them. I will cherish this gift and the many blessings I have received by crossing streams, flying down mountains, and chasing our dreams.

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
- All stage-patients and their caregivers are welcome!
- Access monthly treatment and clinical research updates

CONTACT US

Phone: 1-833-79-CCRAN (22726)

Fax: 905 303 2698

Email: info@ccran.org

Website: CCRAN.org



WHEN:

Every 3rd Sunday of the
month, 1 – 4 pm

WHERE:

Virtually on Zoom

A well-supported patient is a well-coping patient. Together, anything is possible!

Preparation for the 11th Annual Bumrun



Though we're still in the midst of summer, the CCRAN and Bumrun team already have their eyes set on spring 2022. That's right - we're getting our butts in gear and planning for the 11th annual Bumrun!

In July, CCRAN and Bumrun sent out a survey to all registered 2021 participants to understand their thoughts around a virtual or live event in 2022. This feedback will be critical in helping us plan for next year's event, as we are working to create the most engaging and fun-filled user experience for our next Bumrun. Thank you to everyone who took the time to fill out of questionnaire and share their input.

Our preparations continue for Bumrun 2022. Stay tuned for more info coming soon!

Thank you to Bumrun's supporting sponsors!



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