Hello friends:

Welcome to another edition of CCRAN’s newsletter. We’re halfway through 2022, and so far, it has been an extraordinary year for CCRAN!

Already, we’ve had the most successful Bumrun event to date, hosted our first annual "My Colorectal Cancer Coach" Training & Certification Conference, had a conference report published as part of a collective authorship based on our 2021 EAOCRC Virtual Symposium, completed a record number of pCODR/INESSS patient input submissions outside of the colorectal cancer space... and so much more!

We invite you to read through our summer newsletter to hear about what we’ve been up to and learn where we’re going! Thank you and enjoy.

Jessica's Story
CCRN’s Information & Support Group
Colorectal Cancer Awareness Month
Bumrun 2022
"My Colorectal Cancer Consultant" Parts I & II
Heroes’ Headquarters
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EAOCRC Virtual Symposium
And So Much More!

Filomena Servidio-Italiano
President & CEO
Grace Malito
Manager, Administration & Marketing
Daniella Conley
Manager, Communications & Special Initiatives
Frank Pitman
Outreach & Volunteer Coordinator
Mikaela Manna
Clinical Research Updates Coordinator
Jessica's Story

I was told I had colorectal cancer a week after my 37th birthday. Misdiagnosis, surgeries, miscarriage, pain and delays led up to this diagnosis. Doctors dismissed my concern that something was terribly wrong and they assured me I am too young to have cancer.

My nana passed away at age 54 from colon cancer and she too was told she was too young and healthy to have this cancer. Since my parents had no polyps there seemed to be no concern for me. Little did we all know that I have a rare genetic disease that grows lots of polyps. One of my sisters was screened right after me and discovered she had the same disease but minus the cancer. She had no symptoms. My symptoms started a year prior and they evolved; pelvis ache, tailbone pain and bowel habit changes. All were blamed on something other than cancer. I had low iron for years but was told it was from my vegan diet. I just thought my body had a hard time absorbing iron.

I was told I was inoperable and I would likely only live 3-5 more years. My cancer had spread to my lungs. I was told from another cancer patient that I had to connect with Filomena at CCRAN. I emailed her and within a short time she gave me a call which gave me so much hope for my future. Hope was needed for me to continue living with a positive mindset. After 6 months of chemotherapy and feeling extremely healthy I was approved for colon surgery. My colon surgeon removed my entire colon since I had polyps that lined it, leaving me with a temporary ileostomy bag. After that I saw a thoracic surgeon who removed 2 out of the 5 lung nodules.

I thought everything was going smoothly until my next lung nodule removal was cancelled. I was left overwhelmed as I knew something more could be done but I didn’t know how to navigate the medical system. That’s when I reconnected with Filomena at CCRAN to seek her advice. She made it her mission to get me the care and treatments needed.

I am heading into a procedure tomorrow for my lungs. I have plans in the works for treatment after discovering my cancer is also in my spine and rib (but still limited). I feel less overwhelmed knowing I can call, text, or email CCRAN anytime when another issue arises. In addition, CCRAN offers patient zoom meetings where I feel supported and offers new research/trial information plus web seminars with medical professionals who discuss new treatment options. This service is vital for anyone battling this disease as it fills in the gaps of the medical system.

I hope I am able to reach no evidence of disease (NED) this year. I am fighting to live as long as I can for our 3 year old daughter, Vera, who is named after my nana.

JESSICA DASLER
STAGE IV PATIENT
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 every third Sunday of the month to:

- Learn about colorectal cancer resources and clinical research
- 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

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

- Sunday, July 17, 2022
- Sunday, August 21, 2022
- Sunday, September 18, 2022
- Sunday, October 16, 2022
- Sunday, November 20, 2022

All stage-patients and their caregivers are welcome!
In March, CCRAN celebrated Colorectal Cancer Awareness Month with some incredible initiatives to raise awareness and honour all those touched by the disease.

We started the month by participating in a Wellspring Webinar on Wednesday, March 2nd entitled "Young Adult Colorectal Cancer – A Growing Crisis in Canada." The panel included CCRAN’s President & CEO Filomena Servidio-Italiano alongside valued experts Dr. Sharlene Gill, Dr. Michael Raphael, and Dr. Darren Brenner, and the session was moderated by Ms. Louise Binder. The panel discussed the concerns and issues surrounding the rising rates in young adult colorectal cancer and what is being done in response, such as highlighting some of the research efforts being dedicated to this growing area of concern.

On Friday, March 4, we celebrated Dress in Blue Day, which is a call to action to wear blue. Dress in Blue Day, which falls on the first Friday of March each year, encourages participants to start a dialogue with those around them about colorectal cancer, making it an easy way to promote awareness and to honour colorectal cancer patients and survivors. Thank you to everyone who showed their support by wearing blue to spread awareness in your community!

Excitingly, CCRAN launched its first ever Blue Hearts Campaign on Monday, March 7. We designed the Blue Hearts Campaign as a way to expand promotion of colorectal cancer within our online community. As part of the campaign, we asked you to take action by resharing our e-mails and posts and by sharing a ❤️ with everyone you know! We had an outstanding response, and we can’t wait to see you next year to once again kick off the Blue Hearts Campaign on March 7!

Continued on page 5
We were also delighted to host a Patient Education Session on Sunday, March 20 focused on The Management of Metastatic Colorectal Cancer. We were privileged to hear from Dr. Eric Chen, Dr. Calvin Law, Dr. Anand Govindarajan, and Dr. Aaron Pollett on topics such as the medical management of metastatic colorectal cancer, the surgical management of liver and peritoneal metastases, and the utility of biomarker testing. Thank you to all who attended! You can watch the recording of the session here.

Of course, we could not have let Colorectal Cancer Awareness Month pass by without a personal touch from our incredible patients. We were delighted to share special messages from some of our CCRAN Ambassadors. We would like to thank Dan Wadsworth, Roz FitzPatrick, Lucy DeLaat, Theresa Fielding, and Bill McGinley for sharing their thoughts on the importance of colorectal cancer screening in honour of Colorectal Cancer Awareness Month.

Thank you to everyone who celebrated and participated in Colorectal Cancer Awareness Month in any capacity. With the support of our community, we strive to increase awareness of colorectal cancer across Canada and save lives!

See you next year for more incredible initiatives!

Donate to CCRAN and make a meaningful difference!

We appreciate your generous donation to support CCRAN’s Patient & Caregiver Support Programs.

www.ccran.org/donate
This spring, hundreds of people took part in the 11th annual Bumrun all across Canada and made it the most successful Bumrun yet!

On Sunday, April 24th, participants in Halifax, Ottawa, Toronto, Edmonton, and Vancouver walked and ran virtually to raise awareness of colorectal cancer screening.

In Toronto, we were excited to attend the first live Bumrun since 2019 in Queen’s Park! The day began with the Little Bums 500M race for ages 12 and under, followed by our 5KM run, and closed with awards and a post-race breakfast. The in-person event sold out, filling all 500 spots, and we thank everyone for coming out and enjoying a fun-filled morning with us!

On Sunday, May 15th, Bumrun held its first ever live event in Calgary outside of Foothills Medical Centre! We had a tremendous turnout for the inaugural event, and we cannot wait to see how it grows in the future.

In total, CCRAN raised a Bumrun record-breaking $173,621.72!

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 2023!
**CCRAN's May 2022 Patient Education Session:**
The Management of Earlier Stage Colorectal Cancer

On Sunday, May 15th, CCRAN hosted a Patient Education Session focusing on the Management of Earlier Stage Colorectal Cancer.

We were privileged to hear three fantastic expert presentations:

- **Dr. Fayez Quereshy**
  - "Surgical Management of Earlier Stage Colorectal Cancer"

- **Dr. William Chu**
  - "Radiotherapeutic Management of Earlier Stage Colorectal Cancer"

- **Dr. Jennifer Spratlin**
  - "Medical Management of Earlier Stage Colorectal Cancer"

These experts thoroughly discussed minimally invasive surgical procedures, total neoadjuvant therapy, and the role drug therapies are playing in the management of earlier stage disease.

**Click on the photos to the right** to watch the recordings from each session!

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**Dr. Sharlene Gill:**
"How to Flip the Script on Cancer"

In February, Co-Chair of CCRAN's Medical & Scientific Advisory Board, Dr. Sharlene Gill, spoke at the TEDxSurrey event, giving an empowering presentation entitled "How to Flip the Script on Cancer."

Dr. Gill's powerful speech speaks to the importance of taking control, being curious, and having courage when faced with a cancer diagnosis.

Watch Dr. Gill discuss how to approach cancer and what she's learned from her patients [here](#).
"My Colorectal Cancer Coach" Training & Certification Conference

CCRAN was thrilled to host our inaugural "My Colorectal Cancer Coach" Training & Certification Conference from June 14 to 16, 2022.

This conference was a training and certification program for CCRAN's Colorectal Cancer Coaches. Colorectal Cancer Coaches are CCRAN members and experts who undergo annual, mandatory training and certification across the continuum of colorectal cancer care and will then specialize in specific areas (e.g., screening, ostomies, metastatic disease, genomic profiling, biomarkers, early age onset disease, etc.) to help address patient queries from across the country.

Over the course of three days, 20 experts presented on a wide range of topics to ensure that our Coaches have a thorough and well-rounded understanding of the disease and are able to assist others throughout their journey.

In addition to the training and certification program, we opened up the conference to silent viewers so that they too could benefit from the expert presentations.

We are deeply grateful to our expert presenters for sharing their extraordinary expertise with us; to our Coaches for their time, diligence, and enthusiasm over the three days; and to our silent viewers for their interest and attention in the conference and program!

SILENT VIEWER FEEDBACK

"We were able to listen in on a number of the virtual sessions last week. It was absolutely tremendous! What a privilege to hear such experts explain the cutting-edge research that is being conducted. More importantly, it gives hope & encouragement to those who are living with this disease."

Beth & Carol Risto

"Congratulations on a job well done. It was so informative... You have put together a great team and your coaches are obviously well-read, empathic, and committed individuals."

Franca Zumpano
CCRAN is fortunate to have a phenomenal group of trained and certified Colorectal Cancer Coaches. Each Coach has taken on a different portfolio to ensure that their expertise as a team covers many aspects of the journey. Regardless of the nature of the query, we are certain to have a Coach who will help you through it!

You can reach My Colorectal Cancer Coach Program by calling our toll-free line at 1 833 79 CCRAN (22726) or emailing us at info@ccran.org.

Please find below our Colorectal Cancer Coaches and their respective portfolios.

**Introducing CCRAN's 2022 Coaches**

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<th>MY CRC PREVENTION COACH</th>
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<td>Sandra Girard</td>
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<td>Frank Pitman</td>
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<th>MY YOUNG ADULT CRC COACH</th>
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<td>Hayley Painter</td>
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<th>MY LUNG METS COACH</th>
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<th>MY PERITONEAL METS COACH</th>
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<td>Cathy Fox</td>
<td>Filomena Servidio-Italiano</td>
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Heroes’ Headquarters

Heroes’ Headquarters is a special video series where we chat with clinicians and patients in colorectal cancer care. This spring, we released three new episodes with extraordinary patient-clinician duos. Each video offers an inspiring account of a patient’s stage IV journey and the remarkable efforts made by their treating clinician to improve their outcomes.

Click on the hyperlinks in each description to watch each new episode now!

Episode 5:
John Kutkevicius &
Dr. Anand Govindarajan

In episode 5, stage IV survivor John Kutkevicius and surgical oncologist Dr. Anand Govindarajan emphasizes the crucial role of support within the colorectal cancer space and how connecting with a strong network of people who have gone through similar experiences can make all the difference in a patient’s journey.

Episode 4:
Bill McGinley &
Dr. Marcelo Cypel

Episode 4 stars stage IV patient Bill McGinley and thoracic surgical oncologist Dr. Marcelo Cypel, a patient-doctor duo who shows us the importance of joint decision-making. Together, they underscore the significance of treating an individual rather than just the disease.

Episode 6:
Marcelino Dolores & Dr. Eric Chen

In episode 6, we hear from Marcelino Dolores, a stage IV colorectal cancer patient who met medical oncologist Dr. Eric Chen when he was referred for a clinical trial. Together, Marcelino and Dr. Chen exemplify the importance of trust in the clinician-patient relationship.
In April, CCRAN’s first manuscript from our 2021 Early Age Onset Colorectal Cancer Symposium was published in Current Oncology! This publication is collectively authored by the phenomenal expert members of last year’s symposium Steering Committee, who worked tirelessly to bring this publication to fruition.

It also includes CCRAN’s President & CEO, Filomena Servidio-Italiano, whose focus is to eventually reverse this disturbing trend in the rising rates of early age onset colorectal cancer in Canada.

The report, entitled Early-Age-Onset Colorectal Cancer in Canada: Evidence, Issues and Calls to Action, brings awareness to the rising rates of EAOCRC, the need for education around the alarming rates, and the need for a thoughtful discussion around research surrounding earlier screening for the younger population.

It also includes a call to action to improve awareness of risk factors & symptoms and investment in research.

Read this publication here.

CCRAN was delighted to have participated in a January 2022 publication titled Attitudes of Canadian Colorectal Cancer Care Providers Towards Liver Transplantation for Colorectal Liver Metastases: A National Survey.

A study on Living Donor Liver Transplant is currently being conducted at Toronto General Hospital, University Health Network and offers live donor liver transplantation (LDLT) to select patients with unresectable liver metastases.

Approximately half of all colorectal cancer patients develop metastases. In cases where the colorectal metastases are isolated to the liver but are considered unresectable, for patients who qualify, a total liver transplantation might remove all evident disease.

In LDLT, a piece of healthy liver is surgically removed from a living donor and transplanted into the recipient, immediately after the recipient’s diseased liver has been entirely removed. The concept of LDLT is based on the remarkable regenerative capacities of the human liver, as well as the widespread shortage of cadaveric livers for patients awaiting transplant.

Read this publication here.
The rates of early age onset colorectal cancer (EAOCRC) are rising rapidly in Canada. Patients with EAOCRC face a unique set of challenges, and we want to understand why. Therefore, we have developed a survey to gather the valuable experiences of patients diagnosed with early age onset colorectal cancer. This survey can be completed by any colorectal cancer patient or survivor who was diagnosed with colorectal cancer before the age of 50 years (or their caregiver on their behalf). If you are currently over the age of 50 years but were diagnosed with colorectal cancer under the age of 50, you are eligible to complete the survey (or your caregiver can complete the survey on your behalf).

We are kindly requesting that you complete the survey, if you are eligible. You can access the survey here. We thank you for your participation in this survey and for sharing your invaluable experiences with EAOCRC so that we can better support you and others facing the disease. The results of this survey will be used as part of CCRAN's national education and advocacy efforts in response to the rising rates in young adult colorectal cancer.

"The Dignity of Cancer" by Dr. Jennifer Spratlin

No experience with cancer is easy. But even in the difficult times, medical oncologist Dr. Jennifer Spratlin believes there is wisdom and grace to be found in each patient's journey.

"The Dignity of Cancer" is a new blog by Dr. Spratlin, a valued member of CCRAN's Medical & Scientific Advisory Board, in which she highlights the positive lessons and learnings from her cancer patients.

Check out the blog at www.thedignityofcancer.com and follow along on Instagram at @thedignityofcancer!
In response to the rising rates in young adult colorectal cancer and the growing number of young patients seeking support, education, and advocacy for advanced colorectal cancer, CCRAN is proudly hosting the second of a series of symposia dedicated to bringing awareness to this crisis in Canada.

Experts will build on the outcomes of CCRAN’s 2021 Symposium, exploring research initiatives in the rising rates of young adult colorectal cancer. We will also be engaging the leads of the U.S.-based Young Adult Colorectal Cancer Clinics for the sharing of best practices to inform optimal management and care of the EAOCRC patients in Canada. The hope is to initiate and build on a dialogue that speaks to the creation of additional young adult colorectal cancer clinics in Canada based on the unique model established by Sunnybrook Health Sciences Centre.

CCRAN believes this initiative to be of utmost importance in helping to understand and reverse a disturbing trend that is currently plaguing the young colorectal cancer patient population and their families.

Who should participate?
- Patients
- Patient groups
- Caregivers
- Individuals & organizations from the cancer care community
- Primary care physicians
- GI clinicians
- Other healthcare professionals
- Researchers
- Academia
- Policy makers
My Colorectal Cancer Consultant Part I

Are you a newly-diagnosed advanced colorectal cancer patient? If so, check out our online tool, My Colorectal Cancer Consultant!

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 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.

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.

Part I Consultants

Dr. Shady Ashamalla
Colorectal Surgical Oncology

Dr. Christine Brezden-Masley
Medical Oncology

Dr. Paul Karanicolas
Hepatobiliary Surgical Oncology

Dr. Rebecca K.S. Wong
Radiation Oncology
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 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

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.

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.
CCRAN is proud to be an advocacy partner for the Colorectal Cancer Project by 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 colorectalcancerproject.org.

Recommended Reading:
"A Short Primer on Why Cancer Still Sucks" by Dr. David J. Stewart

Dr. David J. Stewart, MD, FRCP(C) is a medical oncologist and Professor of Medicine at the University of Ottawa.

In his new book, A Short Primer on Why Cancer Still Sucks, he aims to answer common but difficult questions about cancer. This book is aimed at patients, decision makers and oncology health care providers.

To learn more or to purchase the book, see here.
There is some exciting work being done on gut microbiota research and how it affects young adult cancer patients and survivors. Two recently-published papers explore the effects that cancer treatment can have on the gut health (and subsequently the psychosocial health) of cancer patients and survivors.

The first paper is entitled "The Chemo-Gut Pilot Study: Associations between Gut Microbiota, Gastrointestinal Symptoms, and Psychosocial Health Outcomes in a Cross-Sectional Sample of Young Adult Cancer Survivors." This research explores the correlation between gut microbiota, GI symptoms, and psychosocial outcomes.

The second paper is "The Use of Prebiotic and Probiotic Interventions for Treating Gastrointestinal and Psychosocial Health Symptoms in Cancer Patients and Survivors: A Systematic Review," which focuses on the use of prebiotic and probiotic interventions to treat GI and psychosocial symptoms.

To learn more, check out The Chemo-Gut Study on Facebook!
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.

Ms. Suzanne Quinn, Chairman
Mr. Mario Appugliesi, Vice Chair
Ms. Shaniah Leduc
Ms. Stephanie Prizzi
Ms. Joy Coulson

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

Mr. Bill McGinley, Chair
Ms. Joy Coulson, Vice-Chair
Mr. Michael Caldeorne
Ms. Sandra Clementi
Ms. Sandra Elhilali
Ms. Sandra Girard
Mr. Robert Hamilton
Mr. Andrew Hare
Mr. John Kutkevicius
Ms. Armina Ligaya
Ms. Robin McGee, PhD

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

Mr. Andrew Hare, Chair
Ms. Ana Bettencourt
Ms. Franca Christodoulou
Ms. Jessica Dasler
Ms. Andrea Jamieson
Mr. Amrit Kooner
Ms. Armina Ligaya
Ms. Hayley Painter
Ms. Marie Taurasi
Ms. Joanne Simmers
Ms. Manna Wescott

CCRAN is privileged to be led by a multidisciplinary Medical & Scientific Advisory Board who keep CCRAN abreast of the latest developments in the management of colorectal cancer.

Dr. Shady Ashamalla, Co-chair
Dr. Sharlene Gill, Co-chair
Dr. Ian Bookman
Dr. Christine Brezden-Masley
Dr. Eric Chen
Dr. William Chu
Dr. Marcelo Cypel
Dr. Gareth Eeson
Dr. Mary De Vera, PhD
Dr. Sam Elfassy
Dr. Mary Jane Esplen
Dr. Anand Govindarajan
Dr. Paul Karanikolas
Dr. Yoo-Joong (Yooj) Ko
Dr. Calvin Law
Dr. Christopher Lieu
Dr. Howard Lim
Dr. Stephanie Michaud, PhD
Dr. Eric Marsden
Dr. Michael Raphael
Dr. Dawn P. Richards, PhD
Dr. Gonzalo Sapisochin
Dr. Daniel Schiller
Dr. Lucas Sideris
Dr. Stephanie Snow
Dr. Jennifer Spratlin
Dr. Patricia Tang
Dr. Mark Vincent
Dr. Petra Wildgoose
Dr. Rebecca K S Wong
Dr. Clarence Wong
Dr. George Zogopoulos

CCRAN
Colorectal Cancer Resource & Action Network
A PATIENT-FOCUSED ORGANIZATION

RISCC
Réseau d’informations et soutien pour le cancer colorectal

905 417 0726
1 833 79 CCRAN (22726)
info@ccran.org
CCRAN.ORG