

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

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Ana Bettencourt with her dog, Leggs.

Grateful patient raises \$3,000 for CCRAN

In the spring of 2019 I was diagnosed with stage four colon cancer that had metastasized to my liver. Two surgeries followed and I spent the next four months recovering.

When I was finally strong enough to pursue treatment options, my referral to the Regional Cancer Centre was refused. They said, "I'm sorry, there's nothing we can do for you, we're full." I was devastated. I reached out to my naturopathic doctor, Eric Marsden, for help. Thankfully, Eric wasted no time in connecting me with Filomena Servidio-Italiano at CCRAN who, in turn, connected me to the team at Sunnybrook Health Sciences Centre.

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Message from our President & CEO



Dear Friends:

In 2006 my father was diagnosed with widespread metastatic disease. He was not able to access the biologic therapies that are accessible today in the management of stage IV disease.

While going through the journey back then, I felt like I had been flung into a dark room with no windows or doors. I was desperately in search of that proverbial light switch. If I could just find the light, I reasoned, we might find an answer for my dad. I never did find that light switch....

My father was very ill and succumbed to his disease in less than three months. When I eventually emerged from that dark and terrible room, I was forever changed and wholly committed to a new cause.

Even as I grieved my father's death, I knew there were so

many more people just like him, so many more daughters, and family members just like me, stumbling around in the dark with their loved ones. I recall thinking if the fight against cancer stops the moment your loved one passes, it's precisely at that moment in time that cancer may declare itself victorious and I wasn't prepared to let that happen. So, I continued the fight and helped found the Colorectal Cancer Resource & Action Network (CCRAN) in 2006, one month after my dad's passing.

In more than a decade and a half of service, CCRAN has changed a great deal. When I read through this newsletter, I can hardly believe what we've accomplished. There is enormous volunteer leadership, so many program partnerships, so much harnessing of new technologies and broadening of initiatives.

The work I started back in August of 2006 with courageous and inspiring women such as Toni Codispoti, and Suzanne Aucoin, has grown too large and too important to be sustained alone. I am proud of, and humbled by the clinicians, patients, and survivors who have been willing to roll up their sleeves to promote CCRAN's mission: to assist others by developing thoughtful, meaningful

initiatives that will better serve Canadians suffering from colorectal cancer by offering a 'SEA' of services through: SUPPORT, EDUCATION AND ADVOCACY.

No one wants to be diagnosed with colorectal cancer or worse, metastatic disease. But once diagnosed, our evidence has shown us that the support patients receive outside of the hospital will help to improve their journey. Advocacy groups such as CCRAN are central to that support network and can help patients to navigate the healthcare system with hope, confidence and courage.

Regardless of how much CCRAN grows, everything we have done, and will continue to do, remains linked to the promise I made in those early days: We will never hesitate to go into that dark room with every patient who has been diagnosed with colorectal cancer; we will stay by their side, and hold their hand, until that light switch is found. And once that light switch is discovered, we will continue to journey in the most evidence-based manner, striving towards improving patient outcomes! SCREEN IT! TREAT IT! BEAT IT! Together, anything is possible.

Sincerely,

A handwritten signature in dark ink that reads "F. Servidio-Italiano". The signature is written in a cursive, flowing style.

Filomena Servidio-Italiano
President & CEO, CCRAN

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OH WHAT A NIGHT!

On October 17, 2019 the Ladies' Auxiliary of the Canadian Italian Business & Professional Association (CIBPA) hosted close to 825 people at the Paramount in Vaughan. The gala event was the largest fundraiser in CCRAN's history and was well-attended by patients and supporters alike.

CCRAN launches programs and advocacy hub online www.ccran.org

Trusting the quality of online information in the medical arena is a challenge. The sheer scope of information available on the web makes it nearly impossible to judge the quality of so many competing sources. CCRAN'S new website, www.ccran.org, includes a programs and advocacy hub that will better serve patients who prefer to access information about their cancer diagnosis and treatment online. Key programs include:

Early age onset colorectal cancer

Screening programs have helped reduce the mortality rate of colorectal cancer cases but in people under the age of 50 cases are on the rise. Approximately 7% of colorectal cancer cases are expected to be diagnosed in people younger than 50, many of them at an advanced stage. CCRAN is committed to promoting education and advocacy for this vulnerable patient population across the country.

My colorectal cancer coach

Getting screened for colorectal cancer or being newly diagnosed can be overwhelming. Having an experienced guide and mentor to help you answer questions along the way is invaluable. That's why CCRAN is launching My Colorectal Cancer Coach program. Coaches are CCRAN members and experts who have received special training and certification across the continuum of colorectal cancer care. Providing one-on-one support and information, they will help you understand your options and will follow up with you on your next steps.

My colorectal cancer consultant

This online tool will provide patients with a personalized treatment guide, including potential therapeutic options based on each individual's diagnosis. The information is not intended to replace medical advice but to help guide a thoughtful discussion with the patient's treating oncologist and help the patient better understand their colorectal cancer diagnosis and potential treatment options.

My Foods for Life



CCRAN has partnered with the American Institute for Cancer Research (AICR) to develop its signature program entitled: *My Foods for Life*. CCRAN's *Foods for Life* Program will provide evidence-based lifestyle recommendations and tasty recipes for Canadians to help reduce their risk of developing colorectal cancer and other cancers, as well as recommendations to follow after receiving a colorectal cancer diagnosis. Nutritional recommendations for the metastatic population are also included in this program.

THANK YOU CIBPA!

On December 3, 2019, at the Old Mill Restaurant in Toronto, CIBPA presented CCRAN with a \$75,000 cheque representing proceeds from the October gala. CIBPA's incredible generosity has given a huge boost to the development of CCRAN's patient programs.





Dr. Shady Ashamalla



Dr. Sharlene Gill

Joint statement from CCRAN'S Medical & Scientific Advisory Board co-chairs

It is with great enthusiasm and optimism that we welcome both patients and practitioners to CCRAN. In a time of great uncertainty and darkness for many, an organization such as this brings light and support when it is truly needed the most.

The Medical & Scientific Advisory Board at CCRAN is tasked with supporting and empowering this organization with the best evidence and practice guidelines available in the management of colorectal cancer.

We have all witnessed the great impact that CCRAN can have on the patient journey and the important support that is offered in such challenging moments. It is this patient advocacy and support that is paramount to the CCRAN mission and underlines all of their initiatives, and it is this same patient support that motivates the entire board to empower CCRAN in their mission to not only support each individual patient but also to support broader initiatives to improve patient care.

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Dr. Sharlene Gill, Co-chair

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DONATE TO CCRAN:

By cheque:

CCRAN, 700-2 Bloor Street West, Toronto, Ontario, M4W 3E2

Online:

www.ccran.org/donate

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Expanding CCRAN's outreach

A personal message from
Mr. Bill McGinley,
Chair, Patient Advisory Council

I had the opportunity this summer to visit a remote part of Ontario. I wondered about the people living there: What do they do when they are diagnosed with colorectal cancer and don't have access to the country's top medical professionals? Where do they and their families go for advocacy and support?

We can't bring everyone who suffers from colorectal cancer to the GTA and we can't create a CCRAN group in every city. But we can use technology to the fullest and harness CCRAN's expertise to create a dynamic delivery model that fulfills education and advocacy needs from coast to coast to coast.

During the more than thirty years I've spent as a management consultant I have become well-practiced at the art of seeing opportunities. My job is to identify where great ideas or products are poised for growth, and then show CEOs how to take the necessary steps to get there. My trained eyes tell me that CCRAN is on the verge of a breakthrough: We don't have to grow too much in order to be that much more beneficial to thousands of other colorectal cancer patients.

And I said yes to serving as Chair of the Patient Advisory Council because I believe in the incredible opportunity at hand: that our patient community can help shape the development of programs, and provide leadership to CCRAN's outreach to new audiences. I look forward to working with all of you to make that happen!

SPECIAL THANKS TO OUR PIONEERING DONORS!

Founded in 2006, CCRAN incorporated as a not-for-profit organization in September 2019 and is awaiting charitable status. CCRAN does not receive any government funding. There are no fees or dues required to access CCRAN's programs and services. Donations to CCRAN, while not yet tax-deductible, will help to fund programs that improve outcomes for colorectal cancer patients and their families.



SYMPOSIUM 2021

CCRAN has convened expert panel to explore early age onset colorectal cancer

While the incidence of colorectal cancer has been declining in Canadians over 50 years of age, recent evidence has shown that rates have been increasing in adults younger than 50.

The Canadian Cancer Registry Data captured colorectal cancer incidence rates from 1997 to 2010, which revealed the following trend of increase:

- 1% per year for people in their 40s
- 2.5% per year for people in their 30s
- 7% per year for people in their 20s

Canadians under 50 are not within the recommended screening age because they are considered to be at low risk for the disease. Sadly, when colorectal cancer is diagnosed in this younger population, it is most commonly in the advanced stages.

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In response to this development, CCRAN is launching an Early Age Onset Colorectal Cancer Awareness and Advocacy Campaign.

Central to the campaign will be a series of symposia, the first of which will be held April 15, 2021, co-chaired by Dr. Shady Ashamalla, Sunnybrook Health Sciences Centre and Dr. Sharlene Gill from the University of British Columbia.

The virtual symposium will bring an expert medical and scientific panel together to explore many facets of this alarming trend including risk factors, disease management, prevention and education.

For more information or to sponsor the Virtual Symposium please contact frank.p@ccran.org.

PHARMACEUTICAL COMPANIES SIGNAL SUPPORT FOR CCRAN

CCRAN is proud to announce that pharmaceutical giants Amgen, Bayer and Taiho have all signed on to sponsor CCRAN initiatives including the 2021 Virtual Symposium and development of the My Colorectal Cancer Consultant program. This kind of support goes a long way toward acknowledging CCRAN's efforts to raise awareness about the needs of colorectal cancer patients.

Helping caregivers find the right words

In 2008, several years before we met, my husband Bill was diagnosed with Stage III colorectal cancer.

With a combination of surgery, chemoradiation, chemotherapy, and careful monitoring—with no detection of spread—he thought he'd beaten the disease for good. A decade later, however, the cancer came back. In 2018 Bill received the diagnosis of Stage IV colorectal cancer with metastatic disease.

This was Bill's second cancer journey, my first. In those early days I cried all the time. I was always crying: imagining myself not waking up beside him every day.

As a caregiver I felt lost and disorganized. Cancer is a whole new world of language unto itself. And we were in a situation where surgery wasn't possible. What happens when they can't cut it out? When you are part of a patient population where complex therapies are the best and only option, understanding them is incredibly important.

I knew that for my husband's sake I had to get past the tears. When we came to CCRAN I soon found the monthly peer support group sessions activated my natural sense of curiosity and helped

me to overcome the fear and negativity.

And when I began to receive the Scientific Notes from CCRAN by email they contained much actionable information and helped me to feel less helpless. In my work I like to be smart and organized—to have the right words. I wanted to use those same skills to help Bill.

With CCRAN's help I gradually acquired the vocabulary. When Bill had conversations with his care team about what avenues of treatment or therapies he might try, I was able to listen purposefully, make sense of the information we were given, and better support his journey.

More than anything, though, I am grateful for how CCRAN has brought us together with other patients. The shared experience and the learning have turned a potentially lonely and isolating battle on its head.

Through the many supportive conversations I've witnessed, and been part of, I have seen despair turn to hope right in front of my eyes. I've watched grown men change their attitudes and say, "I'm not going to be afraid of chemotherapy anymore!" because they were inspired by

another patient's bravery and determination.

And I've been comforted to know I'm not alone, having seen my own journey reflected in other caregivers. There's a woman I'll never forget, because she was so much like me: her husband was calm and she was frantic with notebooks and pens during the monthly support group sessions. "What was that word?" she would ask, or "How do you spell that?"

I thought to myself: this woman is in the right place. She will learn the right words here.



Kim and Bill McGinley
Grateful CCRAN Members

CCRAN PARTNERS WITH QUEBEC CANCER COALITION

The Quebec Cancer Coalition is a group of more than 60 non-profits representing all cancer types and all regions of Quebec, which aims to improve the health care system in Quebec for the good of those afflicted with cancer. CCRAN is proud to be a member of the Quebec Cancer Coalition and a leading advocate for people affected by cancer in order to improve the health care system in cancer in Québec.

Ana's story, continued from page 1

Today, thanks to CCRAN's quick action on my behalf, I am under the care and direction of Medical Oncologist Dr. Michael Raphael. With his thoughtful and thorough care, I'm now participating in an immunotherapy trial and am responding very well to treatment.

During the many months at the regional hospital, and during recovery, I had a lot of time to reflect on life. I realized that there were too many things I had taken for granted. I believed in the possibility of a full recovery and made a promise to myself that when I got back to living normally again, I wanted my life to be extraordinary.

CCRAN and Filomena have been, and continue to be, unwavering in their commitment to advocate, support, educate, and, most importantly, act on behalf of patients like me and their families and caregivers. It is this dedication, compassion and action that drives CCRAN and it's why I decided to spend this past summer organizing a fundraising campaign for CCRAN. I wanted to give back to the organization that had given so much to me. It was also incredibly important to me to spread awareness about the importance of early screening and colon cancer prevention before the age of 50.

With the help of my partner, Gus Valdez, this past September we mobilized a team of local businesses, community partners, friends, family, and our social network to spread the word about our bottle drive. After three weeks we had collected nearly 20,000 bottles and cans and raised nearly \$3,000 for CCRAN.

It was an extraordinarily successful and fun-filled day. I had done more than my fair share of crying since being diagnosed with colorectal cancer, but this time, I cried tears of joy.

The support of CCRAN members, people like you and me, is more important than ever. No matter how little or big the contribution, every penny counts and will help to keep CCRAN going strong so those who are with us today, and those who will be with us in the years ahead, will be supported.

I will never forget how Filomena said "Yes, I will help you," when others said, "I'm sorry, there's nothing we can do for you." Giving back like this is the least I can do.



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ANA BETTENCOURT

