The Young-Onset Colorectal Cancer Center was launched at Dana-Farber Cancer Institute in March 2019 and is one of the first centers in the country dedicated to the care and research of young patients with colorectal cancer. The creation of this ground-breaking Center was spurred by the worrisome uptick in development of this cancer in young and otherwise healthy people. Even more concerning is the fact that no one knows why this is happening.

Increasingly perplexed and saddened by young patient after young patient walking through the doors of Dana-Farber, we decided to tackle this problem head on with the Center’s three-fold mission:

1) Provide expert, multidisciplinary, and comprehensive care to address the unique needs and challenges of young-onset colorectal cancer patients
2) Promote scientific discovery and innovation to better understand the causes of young-onset colorectal cancer and develop new treatments

We’re now on Twitter! Follow us @DFarberYoungCRC

**Patient Spotlight**

**JAIME COWELL**

Mary-Brent Brown (Research & Program Coordinator): Tell us how you learned you had cancer.
Jaime Cowell: I had been sick for a year, going back and forth to the ER and various doctors with extreme intestinal pain. At one of my visits to the ER, an ultrasound discovered what was thought to be diverticulitis. I had it removed with surgery, and when it was biopsied, it came back positive for cancer. My surgeon broke the news to me when I went to have the staples removed from my surgery. It was a very surreal moment. I kind of stopped listening once I heard the word cancer - it was too difficult to comprehend. I definitely went into a state of shock. Thankfully, my mom - who has 30+ years of oncology nursing experience under her belt - was there with me and knew what to ask. She did my listening for me that day.

MBB: What was treatment like for you?
JC: My first 12 rounds of chemo were tough. Fatigue and neuropathy were my biggest hurdles. I tried to stay positive throughout it all - I used to look up jokes to tell all the nurses for when I had to get treatment. It was a regular thing for someone to walk by my chair and ask me what the joke of the day was. My dad usually came with me, and I’d make playlists for our commute and then dance and sing, because I knew that would cheer us both up a bit. I got diagnosed a second time - this time stage 4 - in January 2017. Treatment was a lot harder the second time around, both mentally and physically. I got really nauseous every time, and it was difficult to stay positive. I spent a lot of my time watching TV shows that cheered me up, like The Great British Baking Show. I went back to work before I initially planned to, when I was still going through treatment. That was huge for my mental health. Being able to get back to a semi-normal life made a great impact on my overall outlook of my situation.

MBB: In what ways are you different today than you were before you began your journey?
JC: I struggle with depression and anxiety, but I’m constantly trying to overcome it. There’s always the fear that the cancer will come back, but I decided not to let that fear run my life. I adopted a puppy and bought a house. I got a tattoo I’ve been wanting for years. I travel whenever I can. I try to be happy. Some days are harder than others, but I’ve found that things are easier if you at least try to be happy.

MBB: What was the best and worst advice you got?
JC: So, admittedly, I did not take this advice but that’s kind of how I know it’s good advice - my oncologist told me to fight through the fatigue. To exercise if I could, or even just make myself get up and walk around the house if I had been sitting for too long. I found that my fatigue got (continued on back page)
Colon and rectal cancer usually happen to older people, right? You probably didn’t expect to get this cancer so young, but more and more people are. Colon and rectal cancer rates are increasing 1-3% annually in people younger than 50. The American Cancer Society has even lowered the recommended screening age from 50 to 45 to try to catch cases earlier. Unfortunately, we don’t know why this is happening to more young people. There may be environmental or hereditary causes we don’t know about yet, including the microbiome – the environment of tiny organisms such as bacteria – in your gut to cause cancer growth.

That’s why the Beyond CRC project was created. The goal is to identify the underlying biological mechanisms of cancer cells, identify risk factors for developing colorectal cancer at a young age, and facilitate the development of new therapy options. We asked many young patients at an early appointment to be a part of our biobank so that we can partner with you to form this new longitudinal study of young-onset colorectal cancer patients.

The Beyond CRC project involves three components: clinical and treatment data; tumor, blood, and stool samples; and a comprehensive diet and lifestyle questionnaire. Soon we may ask you for stool samples through a mail-in kit and to fill out the questionnaire. These components will be studied alongside the information in your medical record, a tumor sample we request from wherever you may have had a biopsy or resection done, and blood we ask to collect at your appointment.

Why are more young people getting colorectal cancer?

Colon and rectal cancer usually happen to older people, right? You probably didn’t expect to get this cancer so young, but more and more people are. Colon and rectal cancer rates are increasing 1-3% annually in people younger than 50. The American Cancer Society has even lowered the recommended screening age from 50 to 45 to try to catch cases earlier. Unfortunately, we don’t know why this is happening to more young people. There may be environmental or hereditary causes we don’t know about yet, including the microbiome – the environment of tiny organisms such as bacteria – in your gut to cause cancer growth.

It is absolutely critical that we have all of these different components from as many young-onset colorectal cancer patients as possible if we are to understand why this cancer is happening more frequently in young people. Hopefully this will all come together to identify novel ways to prevent and treat young-onset colorectal cancer.

For Family and Friends

In order to compare cancerous and healthy tissues, we also need to collect specimens from people without cancer tissue. These volunteers need to be adults and cannot have had cancer in the last five years. If your spouse or friends would like to participate, they just need to fill out a health survey and give a small amount of blood.

All of these studies are completely optional, and your participation or non-participation does not affect the quality of your care. If you have any questions call Coordinator Mary-Brent Brown at 617-632-2459 or email Mary-Brent_Brown@dfci.harvard.edu.

INSTITUTE INSIDER

Did you know that there is an audio tour of the art at Dana-Farber? The 40 minute self-guided audio tour consists of 27 stops. You can take the tour in sequence or select only the stops you’re interested in learning more about. Hand-held devices and maps are available in the Shapiro Center for Patients and Families on Yawkey 1, or the tour is available with images online. Smoochers, above, is stop #3.
Meet the Center Staff

**Director:** Kimmie Ng, MD, MPH  
**Hometown:** Wayne, NJ  
**Fun Fact:** I studied classical piano at The Juilliard School in NYC for 7 years during middle and high school.  
**Job description:** I am a medical oncologist who cares for patients with all types of gastrointestinal malignancies. I also lead a clinical and translational research program that focuses on identifying dietary, genetic, and molecular predictors of better survival in patients with colorectal cancer. I wear many additional hats at Dana-Farber, including leading the clinical trials office, directing the gastrointestinal cancer biobank, co-directing the Colon and Rectal Cancer Center, and recently became the Founding Director of the Young-Onset Colorectal Cancer Center.  
**Why I love my job:** I have the honor of caring for the most courageous and resilient patients and helping them navigate the challenging journey of cancer diagnosis and treatment; I treasure the relationships that I have with my patients. I also love working at Dana-Farber because I am surrounded by brilliant and collaborative people who all share the common mission of improving treatment and outcomes for patients with cancer.

**Research Manager:**  
**Lauren Brais, MPH**  
**Hometown:** Mansfield, MA  
**Fun Fact:** I was offered my job at Dana-Farber while I was literally graduating from college – it was an exciting day!  
**Job Description:** My role is to facilitate translational research projects. We work closely with laboratories at Dana-Farber to study questions related to early detection, disease progression, and treatment of various types of gastrointestinal cancers. Our team also facilitates genomic testing on tumor samples and the use of these results for care and clinical trial enrollment.  
**Why I love my job:** Translational research helps to answer important questions in the research of gastrointestinal cancers and provides hope for current and future patients.

**Social Worker:**  
**Katelyn MacDougall, LICSW**  
**Hometown:** Skaneateles, NY  
**Fun Fact:** I was born in Hawaii and the majority of my extended paternal family lives there. Aloha!  
**Job description:** I am an oncology social worker working alongside the medical team, helping patients and families cope with the impact of cancer through professional counseling.

**Research & Program Coordinator:**  
**Mary-Brent Brown**  
**Hometown:** Covington, LA  
**Fun Fact:** I named my dog Neds after the Netherlands, where I studied abroad.  
**Job description:** I speak with young colon and rectal cancer patients about research and support at Dana-Farber. Through the Beyond CRC Project we are trying to decipher why rates of colorectal cancer diagnoses are rising among young people, while the Center supports our patients at every step of their cancer experience.  
**Why I love my job:** My colleagues and I have the same goal: bettering the lives of our patients and their families.

**Administrative Specialist:**  
**Hollis Hanna**  
**Hometown:** Lincoln, RI  
**Fun Fact:** I lived in Walt Disney World for 9 months while participating in their college internship program!  
**Job description:** I specialize in administration tasks supporting Dr. Ng. This provides the opportunity to positively impact patient care by keeping communication lines fluid and efficient between patients, their Dana-Farber doctors, and other health care professionals. I also have been working with the Beyond CRC research team to start the process of building a social media presence!  
**Why I love my job:** I love my job because of the caring connections that are made with patients, as well as colleagues.

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**NEW THROUGH THE CENTER**

- Genetics counseling offered upfront to every patient
- Molecular tumor testing for personalized treatment strategies and possible clinical trial participation
- Dedicated program coordinator for expedited referrals to support services
- Dedicated social worker for counseling support around the many changes throughout treatment
Support & Education

PROGRAM AND RESEARCH COORDINATOR
We understand cancer affects one’s life in many ways so we offer a wide range of support services. We have a dedicated Coordinator who can provide assistance in connecting you to these and help set up appointments. To learn more or if you have questions please call 617-632-2459.

SOCIAL WORK SUPPORT
Facing cancer can be challenging. The disease can affect many parts of your life, and these changes can be distressing. We have a dedicated Young-Onset Social Worker who can provide supportive counseling. To learn more and make an appointment call 617-632-3301.

YOUNG ADULT SUPPORT GROUP
This group is offered twice a month on the 1st and 3rd Wednesday of each month from 5:30-7pm to people in their 20s and 30s who are currently in treatment or have recently completed treatment. You can come alone or joined by a close support person. Registration is required: please contact the facilitator Bruce MacDonald, LICSW at 617-632-5657. Parking is validated in the Dana-Farber Yawkey Garage.

CAREGIVER SUPPORT GROUP
This group is offered on the 3rd Tuesday of each month from 6-7:30pm and 1st Thursday of each month, 12-1:30pm. Learn how to care for yourself while caring for a loved one. Share experiences, information and resources with others who are facing similar challenges. Registration is required: please contact the facilitator Ruth Cope, PhD, LICSW at 617-817-6280. Parking is validated in the Dana-Farber Yawkey Garage.

3) Increase education and awareness of this serious problem to improve prevention and early detection. Together with you, we hope to make significant new advances in how we care for and treat young-onset colorectal cancer.

We know that young patients often feel alone in their cancer journey. We have heard from many of you that you do not see anyone else of similar young age in the waiting rooms or infusion rooms, and this can feel very isolating. One of the goals of the Young-Onset Colorectal Cancer Center is to provide you with a community of other patients and caregivers who are going through a similar experience, so you know you are not alone.

This quarterly newsletter is one of the main tools that we will use to keep you connected to the Center and with each other. We aim to give you resources and helpful tips as you navigate your cancer journey, inform you of the latest research updates about young-onset colorectal cancer, and share personal stories from some of our brave patients. We want this newsletter to be as helpful to you as possible, so please do not hesitate to reach out to us with your questions and suggestions.

Helen Keller once said, “Alone we can do so little; together we can do so much.” We look forward to partnering with you to battle young-onset colorectal cancer.

Sincerely yours,

[Signature]