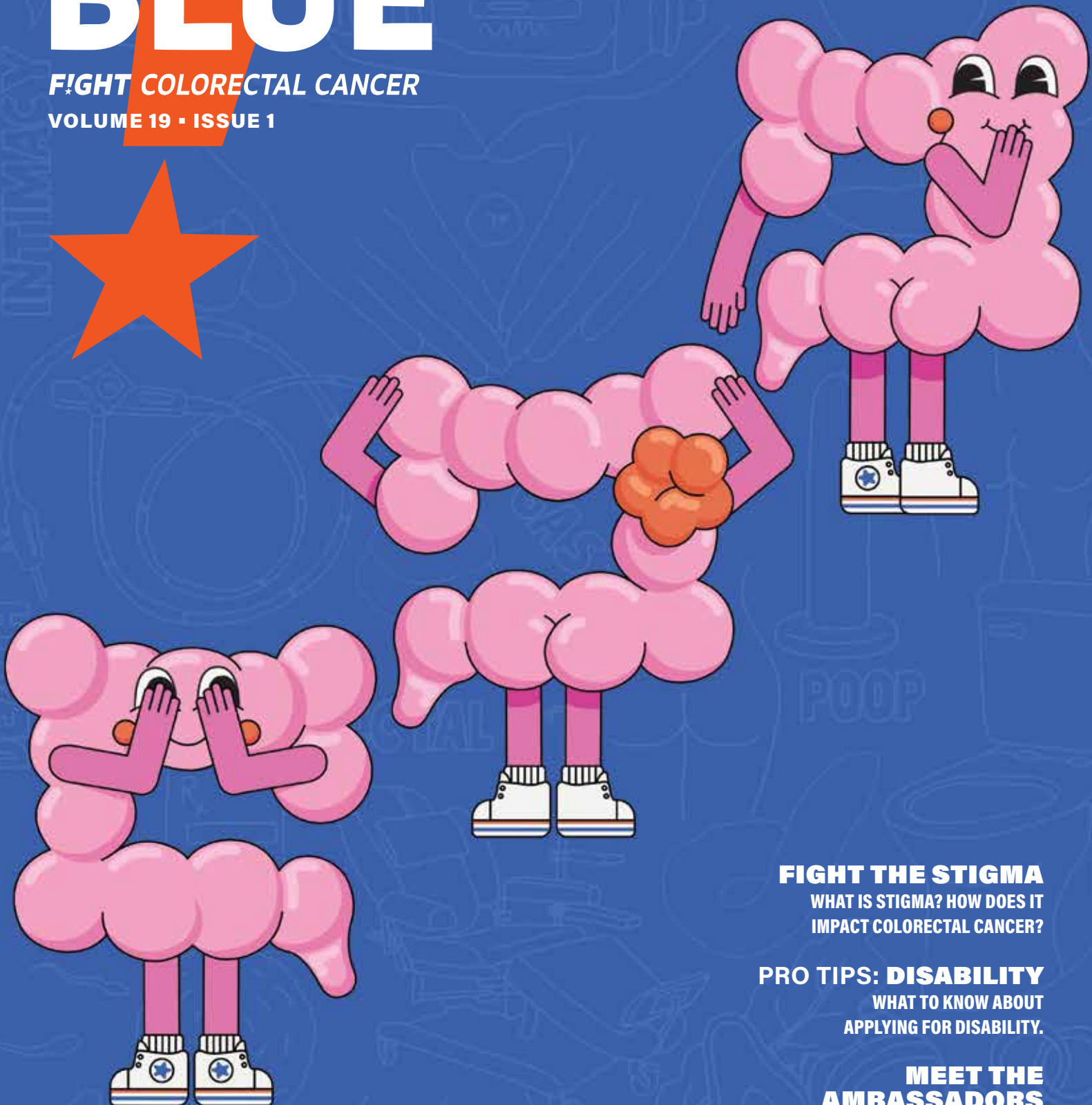


BEYOND BLUE

FIGHT COLORECTAL CANCER

VOLUME 19 • ISSUE 1

*A Magazine for
RELENTLESS CHAMPIONS
OF HOPE IN THE FIGHT AGAINST
COLORECTAL CANCER*



FIGHT THE STIGMA

WHAT IS STIGMA? HOW DOES IT
IMPACT COLORECTAL CANCER?

PRO TIPS: DISABILITY

WHAT TO KNOW ABOUT
APPLYING FOR DISABILITY.

MEET THE AMBASSADORS

FEATURING OUR
2023-24 CLASS

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We FIGHT to cure
colorectal cancer
and serve as relentless
champions of hope for
all affected by this disease
through informed patient
support, impactful policy
change, and breakthrough
research endeavors.

Learn more at FightCRC.org

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Jokes

Why did the toilet paper not want to cross the street?

It would get stuck in the cracks.

Submitted by daughter of Daniel Bloomgarden, survivor and Fight CRC board member

Submit a joke! Email danielle@fightcrc.org.

Word Search

FIGHT THE STIGMA

Z	N	E	I	E	L	U	M	Q	J	C	O	L	Z	H	H	S	V	V	K
D	L	X	W	X	T	J	U	D	G	M	E	N	T	Q	P	H	F	X	E
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M	T	Y	O	V	S	W	G	I	N	A	H	X	W	A	Q	T	A	O	G

Comic

This was An Actual Conversation with a Teenaged Therapy Client Who Accidentally Found Out That I Was Diagnosed With Cancer



CANCER OWL is a creation of stage II survivor Matthew Paul Mewhorter. Visit his work at cancerowl.com. Comic reprinted with permission.

Word Bank

body image	friendship	identity	self care
embarrassment	gross	judgment	struggle
exclusion	help	marginalized	support
fear	hope	scary	therapy



**FOLLOW
ANJEE!**

@anjeedavis



**"I am not the same after cancer.
And that's OK. My strength
came from recognizing I
needed to take time to figure
out what I needed to get my
mind and body healthy."**

Know Thyself

Why advocates must get both
mind and body healthy

I have worked in the cancer community for almost 20 years, and before my own diagnosis with cancer, I used to say, "It's important to know thyself." I had no idea how loaded that phrase was. In truth, no one can prepare you for the mental toll cancer has on your life as a patient and as a caregiver.

It wasn't until a year after I was cancer free, I really started to unravel. My head was a mess, and I certainly didn't know myself. My diagnosis and subsequent surgeries unearthed unexpected fears and trauma I had experienced over 43 years. It all just came bubbling up.

I couldn't fix things on my own, so I turned to therapy and reading every self-help book I could get my hands on. Eighteen months later, my mental well-being is much stronger (it still takes work). I am not the same after cancer. And that's OK. My strength came from recognizing I needed to take time to figure out what I needed to get my mind and body healthy.

Mental health is one of the most stigmatized topics in our world, as many people don't know how to talk about how they're feeling, and if they do, they're afraid of how others will treat them. Being diagnosed with colorectal cancer introduces its own set of stigmas, both public and private, that may increase fear, shame, disgust, and other unpleasant emotions.

In this issue of *Beyond Blue*, we want to unpack this big topic of stigma, with a heavy focus

on mental health. We hope our articles and columns can bring you comfort, and highlight the realities many cancer survivors and caregivers face, and offer hope that there's a way through it.

Remember: It's OK to seek help and support. Your well-being is important. Fighting stigma, finding strength, and getting healthy takes time. Don't rush it. You are not crazy, and you are not alone!

YOURS IN THE FIGHT,

ANJEE DAVIS, MPPA | FIGHT CRC PRESIDENT

P.S. I ran across a gem of a book that helped me understand the toll of a cancer diagnosis on our mental health and what to do to get healthy called "Healing Secondary Trauma," by Trudy Gilbert-Eliot. The book is written for caregivers, therapists, and health care professionals. Gilbert-Eliot visually outlines practical thinking patterns and how they lead to compassion fatigue or secondary trauma. I loved that this book was practical, with checklists and guided questions.



DIGGING DEEPER

READ MY REVIEW

Scan the QR code to read my
blog that reviews the book.



SUBSCRIBE

Get our next issue of *Beyond Blue* mailed to you for **FREE**, and read all our past issues online.

Q: How would you define “stigma?”

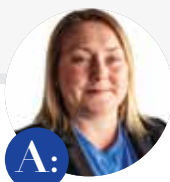
Scan to read and subscribe.



MEREDITH FOSTER

*Stage II Survivor
Illinois*

"I think a stigma is a negative descriptor, association, or feeling that has been attached to something and is generally accepted as truth. I am a real face for what is an abstract concept for many. We can overcome stigmas by sharing our experiences with sincerity, facts, and humor to encourage discussions that are less awkward and more authentic."



ANNA PAYNE

*Stage IV Survivor
Pennsylvania*

"Stigma to me is something that feels taboo or uncomfortable that we as a society defined as not politically correct or polite. It's something we 'shouldn't talk about' because of the way it is viewed and possible judgment it brings. But I say talk about it. I think people sharing their experience and story can help."



THERESA LIPP MASCHKE

*Caregiver
New Jersey*

"I see stigma as something with a negative perception, judgment, or characteristic. By talking about the stigma and acknowledging the elephant in the room, we shine a light on it and bring it closer to the surface, which helps normalize it, so others know they are not alone."

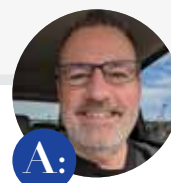


JAY OVERY

Stage II Survivor, Ohio

"Thanks Dr. K. and @UHHospitals for helping in the fight against colorectal cancer! Get screened, it can save your life! Early detection saved mine 6 years ago!! @FightCRC #strongarmselfie"

Follow Jay on X @jaovery



TIM MCDONALD

*Stage IV Survivor
Florida*

"Stigma is something you are stuck with, but it's not part of you. Just how others perceive you. There is no overcoming stigma; there is creating a healthy relationship with it. And we can only control that in ourselves."

Scan to become a Resource Champion!

Resource Champions are dedicated volunteers who help Fight CRC deliver critical awareness and educational resources into their local communities.



The "Ick" Factor

The truth behind my lunch table lie.

I'll never forget what it felt like to sit in my high school cafeteria on a Friday afternoon circa January 2001. I was quickly making up excuses for why I'd chosen to forgo my typical plate from the pasta bar. I lied, "I'm not hungry," and hoped my growling stomach wouldn't give me away. In truth: I was starving. I'd never fasted before and those 20 minutes at the lunch table were the toughest yet. But I didn't want my classmates to know about my colonoscopy the next day, I wasn't ready for their questions, and I didn't want to explain. Plus, I wasn't sure how a group of teenagers would react, and I didn't want to find out. A few weeks later, however, my cover was blown, along with my privacy surrounding my bowel habits. As news spread that I'd been diagnosed with colon cancer, I held my breath for what was to come.

Over 20 years later, many of the memories surrounding the early days of my diagnosis have faded, but the feelings have not. I remember them like it was yesterday. Publicly, I feared what people thought of me—especially my teenage peers—since my story was tied to things like toilets, poop, and the bathroom. It came with an "ick" factor, and I knew it. Plus, I was internalizing shame, embarrassment, and awkwardness—things I've come to realize are all a part of this word called "stigma."

I have a complicated relationship with stigma, and I'd like to think I have come a long way. My embarrassment about getting a colonoscopy and talking about poop went away, and it's no secret that I now have an ostomy bag. I've matured; I've healed; and I've found a community that embraces all the potty talking, poop emojis, and bathroom humor that come with the gig. Yet if I'm being honest, private stigmas still haunt me every day. I still need a lot of education, information, and support to face them.

I hope that wherever you find yourself on this path called colorectal cancer, you will realize you're not alone. I guarantee someone else in our community has felt what you feel. Told the same lie. Wondered the same question. Faced the same feelings. And fought the same fight.

STAY STRONG,

Danielle Ripley-Burgess

DANIELLE RIPLEY-BURGESS
VP OF DISEASE AWARENESS & EDUCATION
CHIEF STORYTELLER



FOLLOW DANIELLE!

@DanielleisB



ABOUT THE EDITOR

Danielle Ripley-Burgess is a 23-year colorectal cancer survivor first diagnosed at age 17. Today, she's in remission. Danielle is an award-winning communications professional and author of *Blush: How I Barely Survived 17*.

Book SHELF

**WRITTEN BY COLORECTAL
CANCER CHAMPIONS**



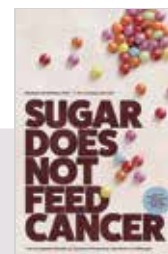
**Little Lizzy and the
Big Blue Parade**

Dr. Lisette Caesar
Colorectal cancer
survivor



**The Best Is Yet
To Come**

Steve Healy
Caregiver to his late
wife, Nikki



**Sugar Does Not
Feed Cancer**

Nichole Andrews, RDN,
aka "The Oncology Dietitian"

EAO CRC **THINK TANK**



On December 1, 2023, alongside co-host Vanderbilt-Ingram Cancer Center and co-sponsor National Cancer Institute (NCI), Fight CRC hosted the Early-Age Onset Colorectal Cancer (EAO CRC) Think Tank. Leveraging innovation and collaboration,

Fight CRC convened leading researchers, medical professionals, and emerging scientists from all over the world with a singular objective: to save young lives from colorectal cancer.

Watch our
Recap Webinar.

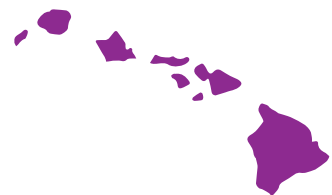


New Catalyst States

The Catalyst Program, a cornerstone of Fight CRC's advocacy initiatives, supports state-level policy change through coalition building and grassroots advocacy. Last November, the program expanded to include Georgia, Hawaii, Missouri, and Nevada. Since launching the program in 2019, Fight CRC has supported advocacy efforts in 12 states and has had bills signed into law in eight states that will help ensure more people have access to colorectal cancer screening.



GEORGIA



HAWAII



MISSOURI



NEVADA

CATALYST
STATE-BY-STATE ADVOCACY
FIGHT COLORECTAL CANCER



To learn more about our Catalyst State-by-State Program, visit **FightCRC.org/Catalyst**.



Research Grant Awarded

Fight CRC and the Collaborative Group of the Americas on Inherited Gastrointestinal Cancer (CGA-IGC) have granted the second **Early Career Award** to Alessandro Mannucci, MD, of the Beckman Research Institute. Dr. Mannucci's work is dedicated to gastrointestinal cancer, with a focus on hereditary cancer syndromes and early-age onset cancers. The awarded research project will center on, "a novel blood test—one that is pragmatic for clinical settings, cost-effective, patient-friendly, and sensitive in detecting EAO CRC."

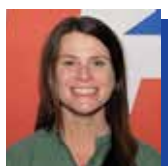
Meet Our New Board Members!



Rob Mills joined Fight CRC as an advocate in honor of his wife Marie. Marie has stage IV colon cancer and is currently going through treatment. Rob's goal as a board member is to drive awareness, early detection, and improved mental health support for patients and their families.



Dr. Cathy Eng is a Professor of Medicine, Hematology, and Oncology; the Co-Director/Co-Leader of GI Oncology Research; and the Director of the Young Adult Cancers Program at Vanderbilt-Ingram Cancer Center. She co-chairs the National Cancer Institute's GI Steering Committee.



Erin Stratton connected with Fight CRC when her dad, Ed, was diagnosed with stage IV colon cancer in 2019. He became a Fight CRC ambassador in 2020. Drawn to the impact of research and the strong support of the Fight CRC community, Erin is an advocate for early-age onset awareness and expanding access to the progressive, life-changing care approach her dad received at Siteman Cancer Center in St. Louis.



Brad Holden was connected with Fight CRC through a friend after his daughter was diagnosed with early-age onset colorectal cancer. He joined Fight CRC to expand access to early screening, advance awareness within the medical community, and raise funds to support research into the causes of early-age onset colorectal cancer.



\$1 MILLION RAISED THROUGH CLIMB FOR A CURE

In an inspiring display of unity, determination, and community support, Fight CRC's Climb for a Cure event achieved a remarkable milestone in 2023 by hitting the \$1 million mark to advance colorectal cancer research. To learn more about this year's fundraising event and how to get involved, go to **FightCRC.org/Climb**.

ADD YOUR VOICE!

MARCH IS COLORECTAL CANCER AWARENESS MONTH



Be a champion.
SHARE YOUR STORY

SCAN HERE
to read and contribute



Be a champion.
TAKE ACTION

SCAN HERE
to join the fight



Be a champion.
DONATE

SCAN HERE
to see options



COLORECTAL CANCER AWARENESS MONTH IS SUPPORTED BY

agenus

AMGEN
Oncology

Braintree
A DIVISION OF BRAIN TRUST

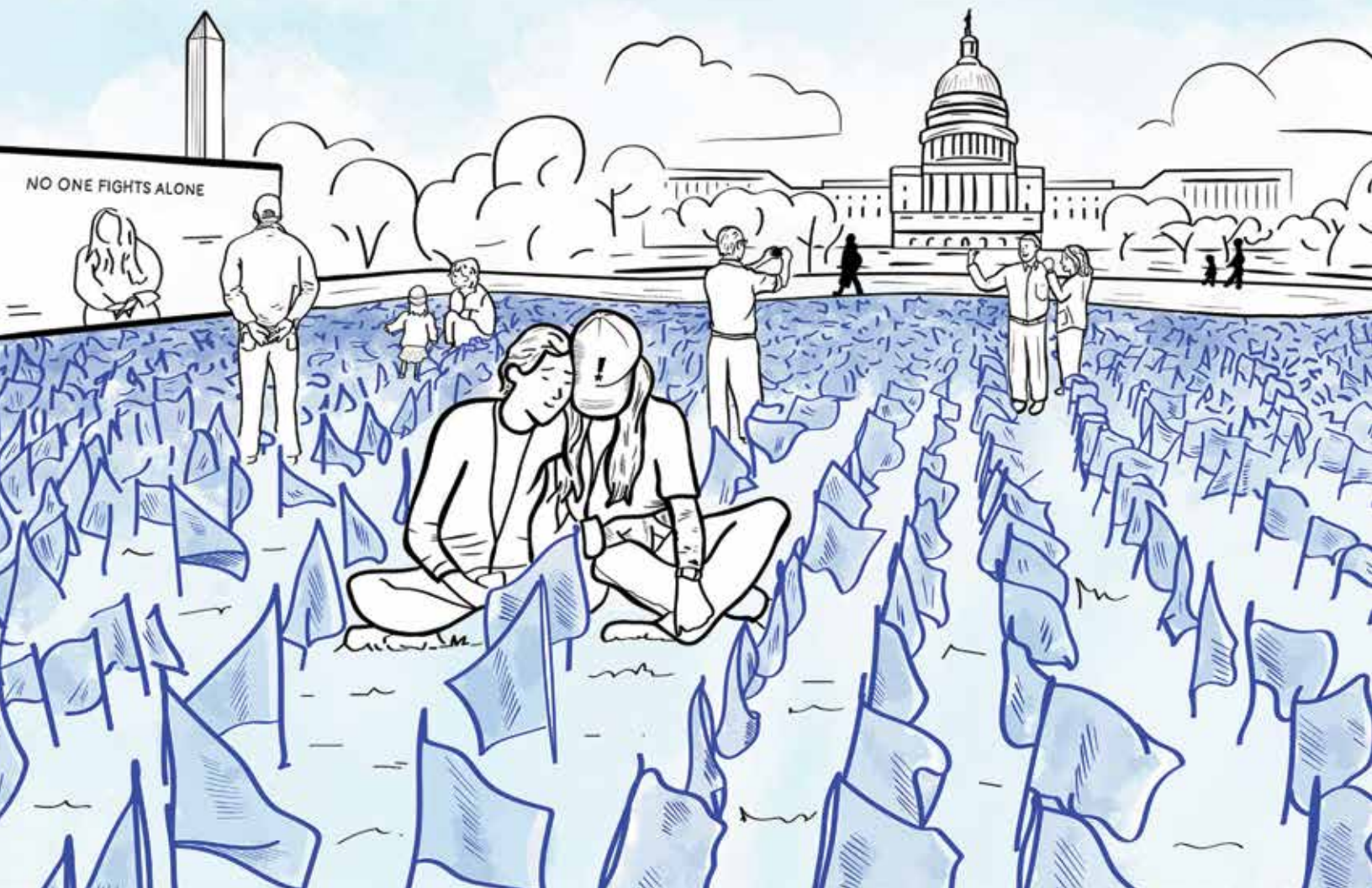
COLORECTAL CANCER
EQUITY FOUNDATION

Daiichi-Sankyo

Genentech
A Member of the Roche Group

janssen

TAIHO
PHARMACEUTICALS, INC.



GETTING HELP

It's normal to not feel OK.

Few life experiences are more scary and stressful than a cancer diagnosis. Cancer treatment primarily focuses on treating physiological aspects of disease; however, cancer's effects extend beyond the purely physical body into mental, social, emotional, intellectual, and spiritual realms of health. Each of these dimensions of psychological and emotional well-being typically fall under the umbrella category of "mental health."

Integrating mental health into comprehensive treatment and survivorship plans is becoming more common as estimates suggest as many as 25% of survivors report symptoms of clinical depression. Numerous surveys have suggested cancer survivors disproportionately suffer from anxiety, cognitive dysfunction, and sleep issues long after treatment has ended. And many survivors would agree coping with the uncertainties of life post-treatment is challenging.

How to know if you need help

The National Institute of Mental Health recommends seeking professional help through a medical provider if you are experiencing symptoms such as thoughts of death or self-harm, depression, difficulty sleeping, appetite changes and/or changes in weight, or the inability to carry out normal daily functions for longer than two weeks.

Your current care team is a great place to start talking about getting help. Additionally, you can search online for free tools for self-assessment and also find resources to aid the process.

Perhaps you are not feeling psychological distress or mental instability, but you are interested in improving your overall state of health and well-being. Help is available for changing your diet and nutrition, daily habits, movement and exercise, sleep routines, or mindset and self-image. Those navigating life post-treatment often also need help.

Options for finding help

Counselors, psychologists, and psychiatrists

If you are experiencing depression, debilitating anxiety, or any of the other symptoms already mentioned, connecting with a mental health service provider like a licensed therapist, counselor, psychologist, or psychiatrist should be your first course of action.

These mental health practitioners can work with you to address psychological distress, help heal emotional trauma, and manage mental health conditions with psychotherapy and/or medication. Your current care providers can assist you in finding a credentialed mental health professional, or you can utilize your insurance provider network for participating providers. A social worker as part of a clinic or facility can also help you find support.

Support, relationships, and other approaches

Caring for your mental health does not always mean you need a clinician. Peer-to-peer support groups (like Fight CRC's Meetups), psychosocial support through close relationships with family and friends, exercise, hobbies, meditation and mindfulness, and journaling are common approaches to improve mental and emotional well-being.

Certified coaching

Another lesser known but growing option is to work with a certified coach (e.g., life coaches, and health and wellness coaches). Coaching is a collaborative process which empowers clients to make behavioral health and wellness changes through techniques in motivational interviewing, reflective listening, and awareness. Unlike therapy, which focuses on events of the past, coaching is future-focused and helps a client access their internal strengths to achieve goals and grow in various areas of their lives to attain higher states of well-being.



ERIKA BILGER

Erika is a 23-year, stage IV colorectal cancer survivor who was diagnosed at age 22, and a certified health and wellness coach serving cancer survivors. Learn more at erikabilger.com.

Coaching is not a replacement for addressing psychological distress, trauma, or prescriptive medication needs, but for survivors looking to amplify their health, well-being, and quality of life, it can be a helpful process for moving forward after cancer. Like therapy, coaching may be a reimbursable service as part of your health benefits, and coaches and therapists can also work as a team to help survivors heal from the past and move forward in their lives.

How to move past stigma and find support

You are not alone. Cancer is hard. If you would like help, but are holding back because you are afraid of what others might think, or you are concerned about the stigma around getting help, know that mental health support for those facing cancer exists for a reason: We need it! Seeking and receiving help is a necessary form of self-care. Help may also be integral to long-term healing. You have the power to take action toward healing.

Another perspective to consider is mental health is one piece of an integrative approach to health and well-being. We are not our bodies alone, but we are also mental, emotional, and spiritual beings. All parts are interrelated, and, thus, caring for our mental and emotional dimensions is also caring for our physical bodies. This is why survivors with psychosocial support report higher quality of life than those without it.

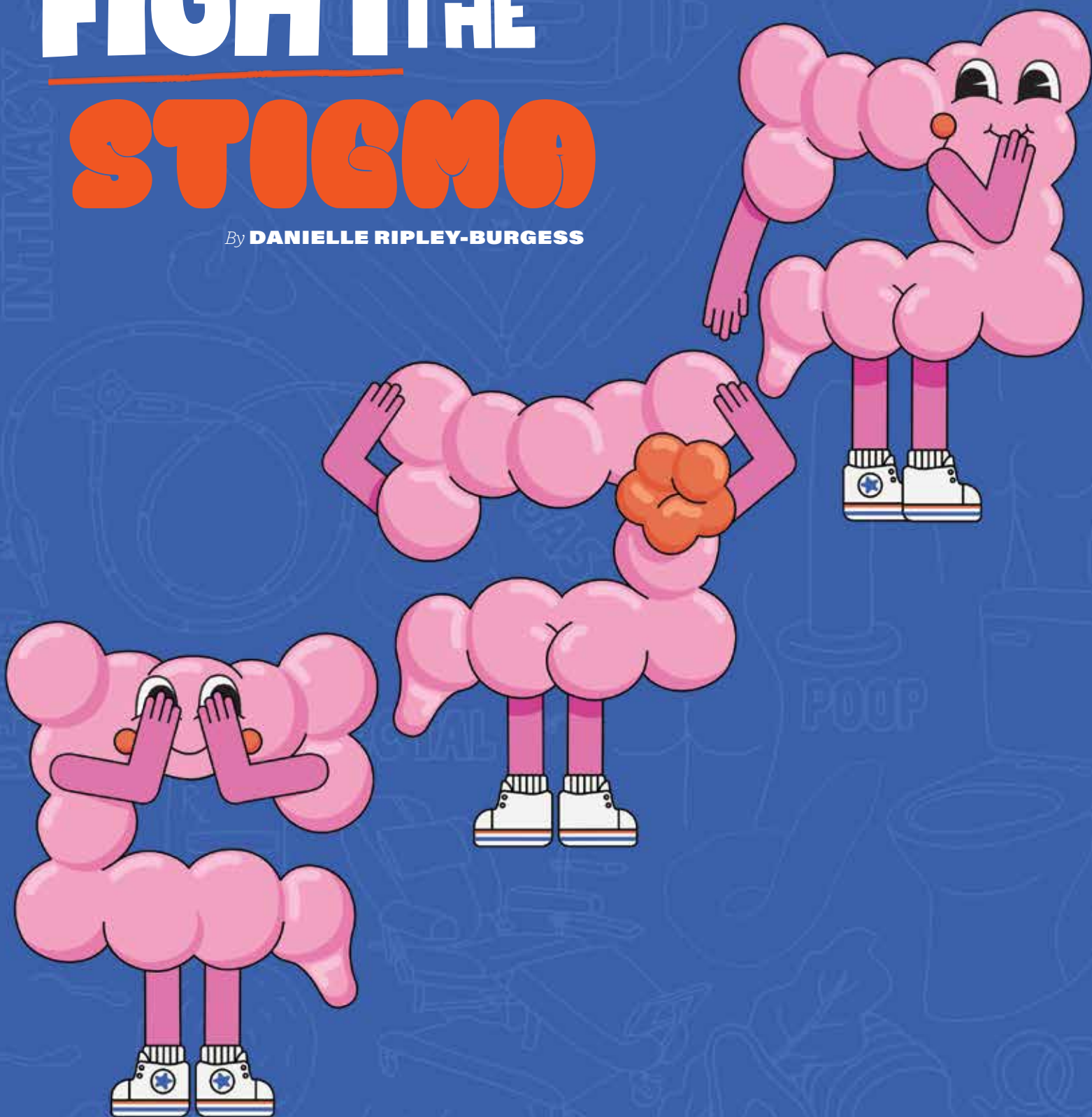
MENTAL HEALTH RESOURCES:

Finding mental health support is for both survivors and caregivers facing colorectal cancer. If you need resources or help in taking the first step, scan this QR code.



FIGHT THE STIGMA

By **DANIELLE RIPLEY-BURGESS**



Many aspects of American culture derive from ancient Greece—from western philosophy, to the Founding Father's ideals of democracy, to the Olympics, and the alarm clock. However, there's another Greek concept that's just as influential and pervasive in our society today: stigma. We hear the word tossed around, but what does it mean and how does it impact our colorectal cancer community?

In Greek culture, stigma literally meant "to carve, to mark as a sign of shame, punishment, or disgrace."¹ The word "stigma" applied to criminals, traitors, and slaves who were physically branded and set apart from the rest of society. Over the years, the physical branding component has dropped from the definition of "stigma," but what has stuck is the sense of disgrace. Pretty harsh.

Fast forward, sociologist Erving Goffman's work on stigma is considered some of the most influential when it comes to modern-day thinking about this concept. His 1963 book, "Stigma: Notes on the Management of Spoiled Identity," is an "excursion into the situation of persons who are unable to conform to standards that society calls normal!" In it, he writes:

"While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind—in the extreme, a person who is quite thoroughly bad, or dangerous, or weak... Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap."

Survivors and caregivers may feel handicapped by stigma and uncomfortable when discussing the body parts where cancer shows up. Or, cancer in general can make them feel like outsiders. Stigma carries physical and mental struggles that not everyone can understand, nor articulate, but are experienced daily.

Cancer stigmas are real

Few patients would describe having cancer as an "undesired difference," as Goffman labeled it, yet deep-down, the description rings true. Having cancer can shift you from feeling like a "whole and usual person to a tainted, discounted one," and especially in a social aspect, when engaging with family or friends who haven't experienced the life-altering effects of cancer.

Those feelings and experiences were validated in 2014 by Drs. Marlow and Wadle, London-based researchers, who published a scale measuring cancer stigma that has since been widely accepted by other cancer researchers around the globe and used to understand and define cancer stigma within a community.

They identified six aspects that go into cancer stigma and are the foundation of the now widely adopted **Cancer Stigma Scale (CASS)**:

- 1. AWKWARDNESS** (e.g., I would find it difficult being around someone with cancer.)
- 2. SEVERITY** (e.g., Once you've had cancer, you're never "normal" again.)
- 3. AVOIDANCE** (e.g., I would distance myself physically from someone with cancer.)
- 4. POLICY OPPOSITION** (e.g., More government funding should be spent on the care and treatment of those with cancer.)
- 5. PERSONAL RESPONSIBILITY** (e.g., A person with cancer is accountable for their condition.)
- 6. FINANCIAL DISCRIMINATION** (e.g., It is acceptable for banks to refuse to make loans to people with cancer.)

Not only did the scale offer a way to measure cancer stigma within certain communities and gauge ways to share cancer prevention messages, but it gave language to many of the public and private stigmas cancer patients face.

Colorectal cancer stigmas

Marlow and Wadle's CASS was not the first research study to look at

stigma. Other studies highlighting the complexities of how stigma intertwines with life had been done, many of them looking at colorectal cancer patients.

"Stigma in Patients with Rectal Cancer: A Community Study" was published 40 years ago and found "Half the patients felt stigmatized, higher proportions being observed among younger patients and among those with a colostomy. Feelings of stigma were associated with poor health, particularly emotional disorders, with the presence of other medical problems, and with disablement."²

Much attention has been given to patients with ostomies, those with rectal cancer, minority communities facing stigma, and male colorectal cancer patients. In the 2011 paper titled, "Stigma, Perceived Blame, Self-Blame, and Depressive Symptoms in Men with Colorectal Cancer," researchers found several insights:

Individuals with CRC may perceive high levels of stigma and blame for several reasons.

- First, CRC may result in the use of a colostomy or ileostomy, which can be noticeable, and may reduce social interaction or lead to situations where other people react in ways that demonstrate disgust. Male rectal cancer survivors who have a stoma feel more stigmatized, have worse social well-being, are more likely to report feeling depressed, and may experience greater suicidal ideation than those without a stoma.
- Second, incontinence and other defecation-related symptoms may result in worse body image and lower quality of life.
- Third, men may experience colonoscopy or examinations of the rectum as embarrassing or threatening to masculine identity, increasing their perceptions of stigma.
- Fourth, men with CRC may also have difficulty adapting to new roles and limitations because of their CRC or its treatment. Physical limitations, change in sexual functioning, and loss of ability to work may lead to feelings of stigma or lower value.³

Regardless of gender, race, sexual orientation, or any other demographic; feelings of shame, low self-worth, and self-blame can be universal and are common amongst colorectal cancer patients.

Private stigma

Today, much of the conversation about stigma centers on the idea of public stigma: the opinions of others and the negative portrayals leading to social exclusion and lack of support.

However, a conversation about stigma isn't complete without addressing the private stigmas that many cancer patients also face. Even if a patient is not experiencing social exclusion, that doesn't mean they're not facing self-stigma and internalizing self-blame or shame for either causing or deserving their disease.

Some struggle with the physical changes they undergo, whether it's living with a stoma, ongoing gas and bowel issues as a result of surgery, facing infertility, accepting physical scars, or experiencing sexual dysfunction because

of treatments. Others carry shame because they ignored modifiable risk factors like diet and exercise, or delayed getting on-time screening or a genetic test.

And while stigma seems unavoidable in many cases, it's important that it not go unchecked and unaddressed. Another study on cancer patients by Drs. Marlow and Wardle found **"higher stigma is associated with greater depression and lower quality of life."**⁴

Showing up

Like it or not, a cancer diagnosis comes with stigma. There's no changing that. But the good news is that there's a community of people who get it, who are also facing and fighting the stigmas, too.

We may or may not bear physical marks that make it obvious that colorectal cancer makes us different from the rest of society, but there's a group of us binding together and fighting off one stigma at a time.



TALK TO US!

WHAT STIGMAS HAVE YOU EXPERIENCED?

Scan to tell us about it in our Community of Champions.

1 Economou M, Bechraki A, Charitsi M. [The stigma of mental illness: historical overview and conceptual approaches]. *Psychiatriki*. 2020 Jan-Mar;31(1):36-46. Greek, Modern. doi: 10.22365/jpsych.2020.311.36. PMID: 32544075.

2 MacDonald LD, Anderson HR. Stigma in patients with rectal cancer: a community study. *J Epidemiol Community Health*. 1984 Dec;38(4):284-90. doi: 10.1136/jech.38.4.284. PMID: 6512480; PMCID: PMC1052370.

3 Phelan SM, Griffin JM, Jackson GL, Zafar SY, Hellerstedt W, Stahre M, Nelson D, Zullig LL, Burgess DJ, van Ryn M. Stigma, perceived blame, self-blame, and depressive symptoms in men with colorectal cancer. *Psychooncology*. 2013 Jan;22(1):65-73. doi: 10.1002/pon.2048. Epub 2011 Sep 26. PMID: 21954081; PMCID: PMC6000725.

4 Laura A.V. Marlow, Jo Waller, Jane Wardle, Does lung cancer attract greater stigma than other cancer types?, *Lung Cancer*, Volume 88, Issue 1, 2015, Pages 104-107, ISSN 0169-5002, <https://doi.org/10.1016/j.lungcan.2015.01.024>. (<https://www.sciencedirect.com/science/article/pii/S0169500215000860>)

5 Cancer stigma and cancer screening attendance: a population based survey in England Charlotte Vrinten, Ailish Gallagher, Jo Waller & Laura A. V. Marlow *BMC Cancer* <https://bmccancer.biomedcentral.com/articles/10.1186/s12885-019-5787-x>

COLORECTAL CANCER STIGMA

LOOKS LIKE



I'M JUST GOING TO SAY "COLON" AND SKIP THE "RECTAL" PART.

Rectal cancer patients face many unique challenges from treatment that often go unnoticed, under-resourced, under-researched, and all-together avoided. Society is more comfortable talking about colons than rectums.

Stigma toward the LGBTQ+ community adds to the stigma of rectal cancer for many, making it uncomfortable and difficult for patients to be open about a rectal cancer diagnosis.



I HAVE AN OSTOMY. I'M AFRAID OTHER PEOPLE SMELL IT, AND MY LIFE IS OVER.

An ostomy is an outward sign that you don't poop like everyone else. Many who face the stigma of ostomy—either publicly and/or privately—struggle with quality-of-life issues and need the support of a community to embrace a new normal and adjust.



CLINICAL TRIALS ARE A LAST RESORT, PLUS, I'M NOT A LAB RAT, NOR DO I TRUST THE SYSTEM.

The misconception of clinical trials and seeing them as a last option has led to delays in new treatment options for patients. Clinical trial enrollment is severely low in overlooked communities, often due to medical mistrust.



I DON'T WANT TO TALK ABOUT GAS, POOP HABITS, AND ISSUES; OR BLOOD IN MY POOP—THAT'S GROSS AND DISGUSTING.

Stigma leads to avoiding critical conversations about changes in bathroom habits because they're seen as a private and "off-limits" topics. This may lead to people not getting screened when a symptom appears; people avoiding screening; and patients hiding a symptom and/or not sharing about a diagnosis out of fear of embarrassment and judgment.



I DON'T NEED TO GET SCREENED. I'M FINE. I'M HEALTHY.

Research shows men face higher stigma toward getting screened compared to women. Some men avoid getting screened because of embarrassment and fear of cultural comments/judgments regarding their sexuality and manliness.



COLORECTAL CANCER IS AN OLD MAN'S DISEASE.

This assumption has led to many misdiagnoses and delays of diagnosis in the early-age onset community. Young people who are not informed about their risk assume they're fine and healthy—and despite their symptoms, providers assume the same.



YOU'RE FINE. YOU'RE TOUGH. TAKE SOME TYLENOL.

Many patients in marginalized racial groups struggle to get taken seriously and receive timely, appropriate care. Research shows there is greater cancer stigma in ethnic minority communities.⁵ This appears in both time to diagnosis and time to treatment.



YOU HAVE CANCER—YOU'RE PROBABLY GOING TO DIE.

Cancer invokes personal fears of death and dying, leading to isolation and exclusion of cancer patients. While celebrity deaths from colorectal cancer raise awareness, they tighten the tie between cancer and death, which is uncomfortable. This can also lead to very real exclusions and financial implications for cancer patients.

IF STIGMAS GO UNCHALLENGED:

- Missed diagnoses and more deaths.
- Fewer early-stage, highly curable, and treatable cancers.
- Delays in treatment and lack of new treatment options.
- Lack of culturally sensitive interventions and resources designed for the communities that need them the most.
- Mental health challenges for patients—depression, isolation, and increased anxiety.
- Continued lags in research funding. Currently, colorectal cancer is the only cancer in the Top 5 cancer types that does NOT have a dedicated research program within the Department of Defense.



HOW HAVE YOU OVERCOME THE STIGMAS THAT COME WITH HAVING COLORECTAL CANCER AS A YOUNG ADULT?

1: **Jason Randall**

*Stage IV survivor
Diagnosed at age 35 in 2018*

As a lifetime ostomate, I often get people who stare at me while at the gym to swim for exercise. With all my scars and ostomy accessories, I try to make it a teachable moment for others by letting them know the importance of screenings by telling my story and how **the ostomy is one of the reasons I'm still alive**. I also loaded my water bottle with advocacy and support stickers to help break the ice and be more relatable. So many who I engage with are dumbfounded that people as young as me can get colorectal cancer and are being diagnosed at the later stages, too.

2: **Nadya Carlson-Bowen**

Caregiver to twin sister Vera who was diagnosed stage IV at age 25 in 2015.

I think as a caregiver, you can't do much other than educate yourself and the people around you, so they are not placed in the same position as your loved ones. I really couldn't do much physically for my sister (like fight the battle she had), but I could educate myself and others to help, especially when she passed. I took many years after she died and advocated for myself and for others (I still do) with the hopes of helping others—even if it just changes one life.

3: **Tammy Monso Figg**

*Stage III survivor
Diagnosed at age 27 in 2002*

Taking every opportunity to educate has always prevailed the stigma. I remember thinking, "Of all cancers, I had to get ass cancer, like really?!" I then realized if I stayed silent, I'd miss out on being an advocate. "Get that rear in the clear" is my most important message. I find once you say you had it, people want to know more because it's not talked about enough.

4: **Misty Watson Lamberson**

*Stage II survivor
Diagnosed at age 29 in 2008*

At times, early on, I certainly struggled with the stigma around being diagnosed with colorectal cancer. I moved past that stigma though after realizing how many people wanted to know about my exact experience and how important it was to be upfront and honest about my symptoms. I found that **the more open and comfortable I became with sharing my story, the more comfortable people became with asking me questions** that led to meaningful conversations about screenings. Really what it all came down to for me was not wanting anyone else to go through what I went through. That is what continues to push me to share my story even 15 years later.

5: **Tina Seymour Demoran**

*Stage I survivor
Diagnosed at age 35 in 2008*

I was diagnosed when I was 35. Dating after getting a divorce five years after being diagnosed and abdominal surgery was definitely different than dating in my 20s. Back then I was scar-free and healthy. After my divorce, trying to figure out when to have the cancer conversation with anyone I dated, let alone let someone new see those scars, was not something I had anticipated when I got divorced or diagnosed. When you're single and young, the world makes you feel like you have to be perfect or you'll end up alone. But I discovered that this was patently untrue. Also, dating the right person for you makes all the difference. We're celebrating 10 years of marriage this year, and looking forward to many more.

6: **Amy Hargrove Goldsbury**

*Stage III survivor
Diagnosed at age 29 in 2003*

I agree that educating people and simply sharing my story has helped break the stigma. If it can happen to me at 29, **it can happen to anyone**. There is always a little shock in my story because of my young age at diagnosis. Molly McMaster Morgoslepov always said, "Get people's attention and then educate them." It's worked for me over the last 20 years!



7: **Wendy Story Lewis**

*Stage IIIIV survivor
Diagnosed at age 49 in 2012*

Fight CRC and The Colon Club have made so many personal stories available. **No one ever wants to feel alone, so we search high and low for someone like ourselves.** Who has walked the walk? What was it like, and what worked and didn't? Priceless. This has helped me and countless others.

8: **Stephen Broussard**

*Stage IV survivor
Diagnosed at age 33 in 2012*

It's amazing how many people want to talk about it or have questions, but are afraid to talk about it. BUTT...if they know I had colorectal cancer, or after I start the conversation, it seems to make it easier for people to open up about it.

9: **Riley Anne**

*Stage IV survivor
Diagnosed at age 24 in 2015*

I was diagnosed stage IV at 24 years old and 17 weeks pregnant. It's difficult to beat that stigma, but the best thing you can do is educate. I have always been open about my story, and I think it's the best thing to do to help people understand this isn't as rare as people may ASSume it is, unfortunately. I was dating someone when I was diagnosed; we got married a year later; then ended up divorced after I was in remission. So dating with cool abdominal scars and follow-up appointments dictating my schedule, as well as my toddler at the time, wasn't what I expected. **But, my now-husband and I met, and it was one of the first things I told him, "Here's my life story."** Also, I find a lot of people learn about their family history when they hear about mine. More times than not, they have colon cancer somewhere in their family and need to get screened before 45.

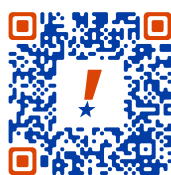
10: **Shannon Costello**

*Stage II survivor
Diagnosed at age 29 in 2015*

The instant I realized the importance of being publicly vocal about colorectal cancer was the instant I overcame any type of stigma associated with it. I also discovered that it had a ripple effect: **When I was vocal, authentic, and made myself available for communication, it encouraged other people to ask the questions they needed to, seek the screenings they were eligible for, and to have the conversations they were embarrassed about with their doctors.** I have been fortunate enough to witness multiple lives being saved by people taking the first step in overcoming stigmas. When all of us are vocal, it gives voices to others—especially to the ones who need it.



All of these people connected with one another through The Colon Club: a space for young adults fighting colorectal cancer. Here are a few ways to dive in and meet others facing this disease way too young:



Scan to get started.

Follow our Instagram account for tips, news, and more.

Join the "Young Survivor Support" group in Community of Champions.

Apply to attend the next Colon Club event: a retreat in June 2025 (more details to come).

TRANSFORMING Colorectal Cancer Clinical Trials

Maia Walker joined the Fight CRC team as lead curator of the Clinical Trial Finder, bringing her unique blend of personal and professional experience. Walker turned her expert research and critical thinking skills toward a cause close to her heart when a dear friend battled metastatic colon cancer.

Today, Walker stands at the forefront of Fight CRC, transforming overwhelming data into practical, life-changing knowledge for colorectal cancer patients and their families.

Fight CRC's Trial Finder, a vision brought to life by the late Dr. Tom Marsilje, is your one-stop destination to discover and learn about pivotal research studies in colorectal cancer. This curated space simplifies your search for clinical trials, allowing you to filter by geography, recruitment status, and more. Stay informed about cutting-edge treatments for late-stage MSS and MSI-H colorectal cancer, all sourced from clinicaltrials.gov, under the specialized guidance of Maia Walker.



MAIA WALKER
Clinical Trial Finder Lead Curator

"Start researching clinical trials as early as possible, at the time of diagnosis. The worst myth is 'clinical trials are a last resource.'"

"There are clinical trials for those newly diagnosed, for those on the third line of treatment, for all stages, etc. There are also trials that might ease side effects from treatments or help family members check to see if they're at increased risk."

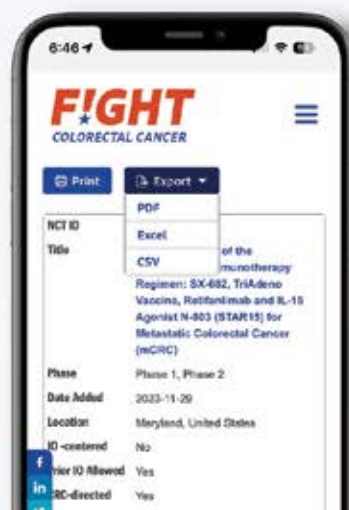
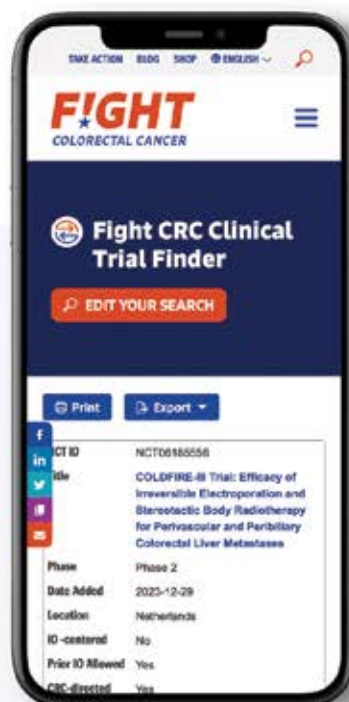
EMPOWER YOUR JOURNEY

Discover cutting-edge clinical trials for colorectal cancer. Visit the Fight CRC Clinical Trial Finder and take an important step toward informed treatment choices.



Discover hope.
SEARCH TRIALS

SCAN HERE
to search



NEW TREATMENT APPROVED



"I hope you all consider participating in clinical trials because we could do so much more in colorectal cancer research if more patients participated."

—Dr. Cathy Eng, MD, FACP, FASCO

Several months ago, the FDA approved a new targeted therapy treatment option for metastatic colorectal cancer patients (fruquintinib)—the first in nearly a decade. As we spoke to Dr. Eng about the drug approval, she emphasized the role patients participating in clinical trials played.

"We cannot move the needle forward without the participation of our patients."

Despite the critical need for patient participation in clinical trials, enrollment in the U.S. is only around 10%-20%.

Contrary to the myth, clinical trials are not a means of last resort. There are many opportunities to participate in innovative research of all kinds—from screening to treatment to survivorship studies.



KNOW YOUR BIOMARKERS

An important step if you're considering a clinical trial is having tumor testing performed so you can learn about what biomarkers are in your tumor, and which studies you may qualify for based on your biomarker status. There are many types of biomarkers, and each patient is unique.

To learn more about biomarkers or how to request biomarker testing, go to [FightCancer.org/Biomarkers](https://fightcancer.org/Biomarkers).



Shaking *the* Shame *and* Stigma

By **THERESA MASCHKE**

People don't want to talk about colons, rectums, or colorectal cancer screenings, but "the more we speak about it, the more we can do about fighting cancer in our community and creating that awareness," says Robert DesJarlait.

In 2013, DesJarlait was having digestive issues, so he saw a specialist who found a tumor in his colon. He was diagnosed with stage I cancer at age 66.

DesJarlait's father passed away from stomach cancer in 1972. As members of the Native community, DesJarlait's family held onto the fear that cancer would one day come back to his family.

Shortly after the discovery of DesJarlait's tumor, the American Indian Cancer Foundation (AICAF) hosted a powwow, which featured a jingle dress healing dance.

The story of the jingle dress is that a man, whose daughter was sick, had a dream where he was instructed by the Creator to make a dress with jingles on it for his daughter. The man did as he was instructed; his daughter wore the jingle dress (also called a medicine dress); and she was healed from her sickness.

At the AICAF powwow, they asked anyone with cancer to walk to the middle and sit on chairs. The jingle dancers came out as DesJarlait was taking a seat. He noticed people were stunned when they saw him sit down for the jingle dress healing dance.

DesJarlait didn't look like the stereotype of someone who has cancer, which is exactly why he felt it was important for people to know about his illness.

"I felt I had to do that to show that nobody is immune from cancer. Anyone can get it," says DesJarlait.

Following DesJarlait's diagnosis, surgery was the only treatment necessary. After surgery, he was instructed to have bloodwork every six months and yearly CT scans.

DesJarlait felt lucky to have "dodged a bullet."

Recurrence

However, in 2016, his oncologist was surprised to find that colon cancer returned when doctors discovered a tumor on DesJarlait's left lobe of his liver.

He remembers sitting in his car and hearing planes flying overhead. People were walking on the street, and as he watched them in his rear-view mirror, DesJarlait thought, "Everything's normal in the world, but I have cancer. How am I going to tell my family this? I have a wife and four kids. That was my biggest concern: How I would tell them that I had cancer?"

In the Native community, there has been a large stigma about talking about cancer. Growing up, DesJarlait, in addition to losing his father to cancer, had a neighbor that died from it.

DesJarlait says, "That was very hush, hush. People didn't want to say the word 'cancer'. The fear was if you talked about it, you would get it."

His 2016 recurrence required treatments that left him with side effects including nausea, diarrhea, and cold sensitivity.

This time, DesJarlait lost his hair: His shoulder-length hair, mustache, and goatee, as well as almost all of his body hair disappeared. Thin eyebrows were all that remained.

The first time he walked bald headed into a powwow was difficult for him.

"I had such long hair. People were shocked to see my bald head. But I had this disease. There's no sense in hiding it. I was showing people that no matter who you are, you can get this disease," DesJarlait says.



That's the message he felt was important to share at the time.

So, DesJarlait started a blog, and he wrote about his daily experiences with cancer. He wanted people on Facebook to be able to follow him and see what was happening. His goal was to educate people on what it's like to go through cancer.

Although Medicare covered all his cancer-related bills, DesJarlait kept copies of them and knows firsthand that fighting cancer is expensive. He feels fortunate that he was able to have access to treatment.

"I had great treatment. I didn't have any problems getting down to Minneapolis," DesJarlait says.

While he had access to affordable care, his travel time for treatment was about an hour and a half each way. He often scheduled appointments after 11am when he was able, but when he had appointments early in the day, he stayed at Hope Lodge.

Since he was retired, treatment did not interfere with DesJarlait's ability to earn a living. He notes that money and insurance are huge barriers to screening within his community. While he had dependable health care coverage, he recognizes that many people in the Native community do not.

"There are disparities. People cannot afford to get medical help," DesJarlait says.



“As scary as colon cancer is, there are other people getting it. As a community, we need to hear more about that from the people diagnosed with the cancer, not the professionals. As survivors, we are not statistics to be grouped together to become a percentage point. The more we speak about it, the more we can do about fighting cancer in our community and creating that awareness.”

**—Robert DesJarlait
Stage IV colon cancer survivor**

Fortunately, within the Native community, there are programs for free screenings. Two Native clinics refer people to Minneapolis to specialists for free colonoscopies.

Despite the shock of the 2016 recurrence, DesJarlait feels like it was a turning point in his life: He was given a second chance.

An artist who got away from his art over the years, DesJarlait had his comeback in 2019, and since then he has been very successful. He began his work in the 1980s with paintings, murals, and illustrations for various Native programs and agencies.

Today his art is tied to his healing process, and he encourages people to continue with or rediscover their talents and abilities after having cancer rather than giving them up.

Native community

The American Indian/Alaska Native population is among the top groups with the highest risk and incidence for colorectal cancer.

Screening delays are a regular occurrence due to a lack of staff and referral systems, and making an appointment with a health care provider can be difficult because of this. Access to screening facilities is also a barrier as it can be an excess of over an hour away to receive a colonoscopy, according to the AICAF, one of Fight CRC's partners, is working hard to raise awareness and garner support for the Native community's needs.

Talking about colorectal cancer

DesJarlait's story has a happy ending: In February 2022, he was declared cancer free.

It's important for him to talk about his personal experience because he believes there is still a stigma of having cancer, and also a stigma of talking about it. For several years, DesJarlait traveled with the AICAF to powwows where he gave a speech about colon cancer and encouraged the Native community to be screened.

He knows that talking and writing about his colon cancer diagnosis has opened the door for others to come forward and talk about their own cancer. DesJarlait knows there needs to be more dialogue about colorectal cancer, “to me, it's still a huge issue,” so he tells his story so that others know how important screening is. **!**



For more information, check out americanindiancancer.org.



MEDICALLY REVIEWED
RESOURCES
you can trust

Hot off the Press

Check out the newest materials or information we've added to our Resource Library!



BIOMARKERS VIDEO:

Learn about what biomarkers are and how they impact your treatment plan.



WEBINAR REPLAYS:

Watch or read the transcripts of all past webinars.



GET RESOURCES

Check out all our patient resources.

Scan this QR code or visit

FightCRC.org/Resources

YOUR GUIDE *in the* FIGHT



Meetups

Fight CRC's meetups are online gatherings open to anyone within the colorectal cancer community: survivors, caregivers, loved ones, and medical professionals.

Everyone is welcome.



We host three to four meetups each month, and one Mega Meetup each month for specific patient communities. Scan to see upcoming dates and reserve your spot.

ATTEND A MEETUP

Monthly Webinars

Our monthly webinar series features experts alongside patients who dive into conversations about relevant topics that colorectal cancer patients and caregivers face.

During live Q&A, experts answer burning questions and offer real-time resources for getting help and finding support.



REGISTER FOR A WEBINAR



Waiting Room Materials

Are you a medical professional wanting to supply your patients with brochures and educational materials?

Or are you a patient wanting to connect your medical team to Fight CRC? Reach out to us to get our brochures, magazines, and posters into your doctor's office.

Contact patientinfo@fightcrc.org for details.

Pelvic Floor Physical Therapy

The pelvic floor plays a crucial role in our lives, but it's an often neglected area of our bodies. Many colorectal cancer patients experience pain, incontinence issues, constipation, sexual dysfunction, and other conditions as a result of cancer treatments like radiation, surgery, or both. But, there's such a stigma attached to this area, and these side effects, many patients—and caregivers—suffer in silence.

Fighting through awkwardness and reaching out for support when it comes to the pelvic floor is a good first step in fighting the stigma. Meg Schwartz, PT, DPT specializes in pelvic floor health and helping patients restore and heal their pelvic floors.

Q I've heard some patients talking about pelvic floor physical therapy, but nobody on my care team has brought it up to me. Should I consider it?

A Yes! Pelvic floor physical therapy is a specialization of physical therapy focusing on all the structures—including bones, muscles, ligaments and tendons—related to the functioning of your bladder, bowel, and sexual function. It's a therapy everyone can benefit from, especially cancer patients.

Q What if my doctor doesn't recommend it?

A Many states have direct access for physical therapy services, meaning you don't need a doctor's referral to seek out a physical therapist. Even if your doctor doesn't bring it up, you can ask for a referral or, if your state permits, call a physical therapist directly.

If your doctor doesn't support pelvic floor physical therapy, I would strongly encourage you to advocate for yourself and tell them this is something you would like to seek treatment for to ensure optimal recovery and the highest quality of life post treatment.

Q Is it for both men and women?

A Because both men and women have pelvic floors, both need pelvic floor rehab. Everyone deserves a healthy, happy pelvic floor! It's something that could potentially benefit all patients.

Q I've heard it can help with sexual health, but is that all? What are some other reasons a colorectal cancer survivor should consider it?

A Sexual health is one aspect of pelvic health, but certainly not the only one. Bladder and bowel health are also crucial areas we address, along with orthopedic considerations including spinal, hip, and rib cage mobility.

For example, rehab considerations for a colorectal cancer survivor would include: return to movement and function, breathing and spinal mobility, scar mobility, pressure management strategies for hernia prevention, return to good bowel and bladder habits, as well as management of any pelvic pain and sexual health.



Q What happens during a visit?

A Our sessions start with hearing about your journey, establishing baseline bowel, bladder, and sexual function, and establishing your goals. Then, we provide education about the pelvic floor and how that pertains to your specific treatment.

Then, with consent, we perform a manual/hands on component, which is often an external and internal pelvic floor assessment. This helps us determine tension, strength, and coordination. It's always a patient's choice when it comes to any sort of exam, so although this is a helpful step in providing the most thorough assessment, if a patient isn't comfortable, it doesn't have to be completed.

Providing an appropriate home exercise program with appropriate exercise/stretches to support and strengthen is essential to optimal outcomes.

Q How can I find a pelvic floor physical therapy specialist in my area? What if nobody is in my area?

A You can search your area at **pelvicrehab.com**; this is a directory of pelvic health providers all over the U.S. If there is nobody in your area, some providers do offer virtual consults. Going to an orthopedic physical therapist to address the orthopedic concerns including hip and spinal mobility and strength can also be helpful. A virtual consult with a pelvic floor physical therapist or orthopedic physical therapist wouldn't provide you with the information an internal pelvic floor assessment would, but it could still be beneficial.

Q When in my treatment journey should it be considered?

A Ideally, prior to starting any treatment. Prehab is important to determine functional baselines, improve functional outcomes, and decrease the risk of postoperative complications. Having good bowel and bladder habits prior to surgery will enable a smoother recovery.

Following surgery/treatment, there will likely be activity restrictions, so make sure to follow any guidelines set by your provider. Once cleared for activity, seek out a pelvic health physical therapist to initiate treatment.



SCAN TO
WATCH.

Learn more about pelvic floor physical therapy from our webinar replay.



MEG SCHWARTZ, PT, DPT

Empower Your Pelvis—Physical Therapy, Health & Wellness
Learn more at **EmpowerYourPelvis.com**.

navigating disability insurance

Going on disability can be a tough decision and one that sometimes comes with stigma of its own. But it's been helpful to many patients who need it. And just like any other aspect of fighting colorectal cancer, if you're considering applying for disability, you're not alone.

There are several benefit programs for people who are unable to work due to physical and/or mental illnesses and disabilities. Disability benefits are for people who have a qualifying disability/disabilities that keep them from earning wages. If you can't work due to a cancer diagnosis, or treatment or surgery effect, you may be eligible for financial support from these programs. In general, any stage IV cancer or terminal cancer will qualify a person to receive disability benefits. Our partners at Triage Cancer have a library of resources that explain disability insurance options, how to apply, how to appeal a denial of benefits, how disability insurance works with other benefits and legal protections, and other important information.

**TRIAGE
CANCER**
Visit Triage Cancer's
Cancer + Disability Resources



CAROLE MOTYCKA

Stage IV Survivor

I was diagnosed in April 2016 with stage IV colorectal cancer. I started chemo immediately and as a result, quickly became unable to do my job due to the severity of the side effects of the treatment. I applied for long-term disability from the start and qualified for Medicaid insurance due to my disease's incurable nature. Because of the metastatic status of my cancer, I was approved quickly and began receiving benefits. The benefits continued through the duration of my treatments of chemotherapy, surgeries, and follow-up treatments. I was able to return to work five years after my diagnosis and ended my benefits.

From my experience, I would encourage anyone with a late-stage diagnosis to consider applying for benefits. Surviving cancer is hard. We should do whatever we can to reduce stress and allow our focus to be on our treatments, personal mental health, and self-care. Anything we can do to eliminate challenges and lighten the burden of cancer is something I recommend. Additionally, I encourage anyone considering applying for Social Security to be overly prepared with documentation. Have all your records together including photo IDs, birth certificates, Social Security card, marriage certificates, bank account information, tax information, and other legal documentation you may need ready to go. This will eliminate the need for several trips or reviews and will expedite the approval process. Additionally, when you schedule your appointment at the office or online, have someone there to help navigate it with you. Two sets of ears are better than one!



JJ Singleton

Stage IV Survivor

I applied for short-term disability as soon as I was diagnosed in September 2015 because I couldn't do my job on chemo. I applied for total disability and SSDI in June 2016 when I found out my cancer was back and incurable.

At first it was denied. My mom and I got help from my cancer center's navigator and got it approved, but it took two months to all get worked out. Having an incurable and terminal diagnosis actually helped fast-track it.

I'd tell anyone who is hesitant and/or embarrassed about applying for disability that it's a normal feeling—especially for me as I was 28 years old when I got on total disability. It made me feel bad, and still does to this day at times, but I try to remind myself these thoughts are normal. Being on disability doesn't take away from me as a person, it actually allows me to put all my effort and strength into the challenges of continuing to fight cancer and live by taking some of the financial pressure and weight off me and my family.

The "L" WORD

Every year in March, Fight CRC hosts Call-on Congress, an event that brings advocates from across the country to Washington, D.C., to meet with their elected officials. Advocates share their stories and advocate—or lobby—for policies important to the colorectal cancer community.

Congress is responsible for policies that impact many facets of colorectal cancer care, from programs that regulate access to screening to deciding the amount of federal dollars that get applied to colorectal cancer research. Call-on Congress is an opportunity for advocates to meet with their representatives and ask them to become champions for our legislative priorities and support our cause.

Admittedly, we don't use the term "lobbying" when we explain what we're doing at Call-on Congress, but in its purest form, that's exactly what we're doing. We're sending in advocates—regular people from our community—in person and via email with action alerts, to fight for what's critical to our cause. We share our stories to be heard. Our goal is to secure funding because we know it is critical to saving lives.

I get it: lobbying often gets a bad rap. For many people, the word "lobbying" evokes images of a slick guy in an expensive suit making a backroom deal on behalf of some evil industry. As a former lobbyist, I often found myself saying I was a "consultant" or "government relations professional" to avoid the stigma that came with the "L" word. I was advocating

for cancer patients through the profession of lobbying, yet unless I had a chance to really explain and unpack it, I avoided using the "L" word more times than I can count.

But, as a former lobbyist, I also know that lobbying doesn't have to be a dirty word because it is, in fact, a critical part of our political system...especially when done with transparency, honesty, and integrity. As a lobbyist, I helped a patient advocacy organization increase funding for medical research by millions of dollars. And there are countless other lobbyists doing similar work, fighting the stigma associated with their job titles because they understand how many lives are at stake if they don't act and ask.

Our Founding Fathers created a government "of the people, by the people, for the people." Members of Congress are elected to represent the needs of their constituents. If we don't lobby them and tell them what we need, how can we expect them to know? We can't.

Our elected officials and their staff need to hear from experts in the topics they are developing policy around. Whether you are a survivor, caregiver, loved one, or medical professional, you are one

of the experts in colorectal cancer. Your story is a powerful tool that can help policymakers understand the colorectal cancer experience. It is important you use it.

We're also aware that even if we tackle the stigma of lobbying, there's still the question of advocacy these days: "What's the point? Congress is such a mess, is it even worth it engaging?"

It's a fair question given the small piece of Congress' day-to-day activities we see covered on the news, but the answer is an unequivocal "yes!" Despite what you may hear on the news or see on social media, work is still being done on Capitol Hill. Every day, lobbyists are meeting with members of Congress to present their needs and requests. We must keep going and showing up so our voice doesn't get lost and drowned out from the many other requests being made.

At the very least, Congress must pass a bill to fund the federal government each year, and that is an important opportunity to direct funds toward colorectal cancer screening and research programs.

Regardless of what is or isn't happening in Congress, Fight CRC is committed to identifying and developing champions for colorectal cancer. We understand that we must raise up grassroots advocates—lobbyists—like you and me so our stories get heard and our priorities taken seriously.

Don't let stigma of lobbying or the eyeroll that comes from watching D.C. news coverage get in the way of you making an impact. Lobbying doesn't have to be a dirty word. No matter how crazy things may look on the news, there are still ways for us to create meaningful change. We can, and we must!



JOIN US

BE AN ADVOCATE

Visit CallonCongress.org for details.



MOLLY MCDONNELL is Fight Colorectal Cancer's Director of Advocacy

FOLLOW MOLLY!

@MollyFightCRC



INTRODUCING THE ★ AMBASSADORS

Each year, Fight CRC selects individuals to become ambassadors and share their stories to put a “face” to the disease. Here's our class of 2023-24!



Roberto Batista de Souza Pinto

"I fight for awareness and continuous research on fighting colorectal cancer."

New Jersey

Caregiver



Jack Birren

"I fight for the people who can't, and for my family."

Wisconsin

STAGE III SURVIVOR

ENTERED THE FIGHT:

12/3/2016; Age 39

@jackbirren

@nocolonstilroln



Meredith Foster

"I fight for all the good years of life that everyone is entitled to. I fight so that someday, no one will have to endure the heartache and physical trauma that comes with battling cancer. More specifically, I fight for young women who could be caught unaware and left feeling isolated or ashamed."

Illinois

STAGE III SURVIVOR

ENTERED THE FIGHT:

7/28/2022; Age 41

@mrosef8



Karen Montieth

"I fight for those who are battling and can't fight for themselves. I fight so more resources get directed to colorectal cancer and so policy changes will be made to help decrease the numbers of those being diagnosed too late. I fight so no one will have to go through the struggle I have had to endure."

North Carolina

STAGE III SURVIVOR

ENTERED THE FIGHT:

11/4/2021; Age 40

@karenmontieth7

@ccsurvivor2022



Jess Fox

"I fight for those who are 'too young' to be eligible for the necessary screenings. Statistics continue to show that younger and younger people are being affected by CRC, and our recommended age for screenings should reflect this. Early screenings will lead to diagnosing CRC at an early stage, and ultimately, saving more lives. I also fight for those who don't know their full family health history due to an absent parent, adoption, or even poor family health records. I never knew my father, and considering that I have zero risk factors or history of CRC on my mother's side, I'm left wondering if my father's genetics could have played a role."

Ohio

STAGE IV SURVIVOR

ENTERED THE FIGHT:

12/16/2022; Age 44

@lady_fox_



Jameelah Mahmoud

"I fight for awareness! And my community."

Wisconsin

STAGE III SURVIVOR

Entered the fight:

4/20/2019; Age 33

@meelah_iz_golden



Terence Pollard

"I fight for the ones who have lost their battles. I am working hard to inform and inspire others that a diagnosis is not final."

Florida

STAGE III SURVIVOR

Entered the fight: 4/4/2017; Age 52

@authorterence



Krystal Gurnell

"I'm fighting for the future of my family; my maternal grandmother and my mother had colorectal cancer. I'm also fighting for awareness and for those who have cancer."

Virginia

CAREGIVER

@krysglo



Tami Pangelina

"I fight for more awareness, to raise funds for research, to break down the stigma of colorectal cancer, and to make a difference."

California

CAREGIVER

@tamisartcreations

@Tamis Art Creations



Anna Payne

"I fight for education, awareness, and for others to be able to save themselves: better access to screening and lowering the screening age."

Pennsylvania

STAGE IV SURVIVOR

ENTERED THE FIGHT:

7/21/2021; Age 34

@apayne226

@AnnaPayne4PA



Ashley Pedro

"I fight for everyone that has cancer—no matter what type."

Nebraska

STAGE IV SURVIVOR

ENTERED THE FIGHT:

2/24/2021; Age 33

@ashleypedrophotography

@AshNPedro



Alecia Mandal

"I fight for everyone's right to cancer treatment and care."

Illinois

STAGE IV SURVIVOR

ENTERED THE FIGHT:

8/27/2020; Age 52

@tetemandal1968

@alecia_mandal

@tetemand1968



Ellen Tappin

"I fight for an end to CRC and to bring awareness to the statistics for those who are living with CRC and those who will be diagnosed by 2030 if more funding for research and awareness is not provided by Congress."

Maryland

STAGE III SURVIVOR

ENTERED THE FIGHT:

9/17/2020; Age 64

@ellen.tappin

@tappie4



Amanda Webb

"I fight for early-onset patients, survivors, and loved ones that we have lost to colorectal cancer. I also fight for Mariana Gantus Wall, my cancer friend who we lost in February 2023. I fight for my cancer bestie, Lyndee."

California

STAGE IV SURVIVOR

ENTERED THE FIGHT:

5/20/2021; Age 36

@webb5858



David Sheir

"I fight for peace of mind, positive memories with loved ones, health, and living a full life."

Florida

STAGE III SURVIVOR

ENTERED THE FIGHT:

11/7/2019; Age 51

@DavidSheir

@MortgageMonitor

Join the Fight at **FIGHTCRC.ORG** 29

Be a Champion

**Are you ready to
become a relentless
champion alongside
Fight CRC?**

**We have many ways for
you to get involved!**



Join Community of Champions

Community of Champions is not just another social media platform. It is your gathering place for connection, resources, and practical tips from those who understand what you are going through. Find your community within the community. It's easy to get started!



Volunteer

Get connected with your local community to see what kinds of things are happening with Fight CRC in your area! Volunteer opportunities vary in time commitment, from simple day-to-day activities to weekly or one-time commitments.



Become an Ambassador

Ambassadors serve a one-year term exclusively representing the Fight CRC community through passionate and intentional engagement, both virtually and in-person. Applications open in March for our 2024-25 group!



Fundraise for the Cure

Need ideas for starting your own fundraiser? Birthdays, cancer anniversary, and honoring a loved one are a few places to start! We are also kicking off [Event] for a Cure, which introduces many new ways to raise funds for this critical cause.



Take Action: Email Congress!

If we don't raise our voices, no one else is going to do it for us! We've made it easy to take action. Right now—today—visit our website and follow the guided steps that help you email your member of Congress, asking him/her to increase access to colorectal cancer screening by increasing funding for the CDC's Colorectal Cancer Control Program and support a Colorectal Cancer Research Program at the Department of Defense!



Scan to get started



Upcoming **Events**



Virtually Take Action for Call-on Congress

March 10-12, 2024

We are meeting with our elected officials in person for the first time since 2019! Call-on Congress is an event where colon and rectal cancer survivors, caregivers, and loved ones from all over the U.S. unite to make their voices heard in Washington, D.C. We demand that policymakers act. You can join us from home. Take action! Learn how at CallonCongress.org.

Virtual Global Think Tank

Fight CRC is committed to uniting organizations, patient advocates, and experts in oncology, epidemiology, genetics, industry, and academia to tackle crucial gaps in early-age onset colorectal cancer research. The Virtual Global Think Tank, an extension of the December 2023 Early-Age Onset Think Tank in Nashville, will further convene minds to address this issue this summer.



[Event] for a Cure

Support Fight CRC's mission with your [Event] for a Cure. Unlike climbing a mountain, you decide the event type, location, and timing. Take charge of planning and decisions, making hosting as simple or elaborate as you prefer. Learn more and apply for a Cure Grant to help fund your idea to lead to an impactful community event. Apply today! Get started at FightCRC.org.



Learn more at FightCRC.org/Events.

LOOKING AHEAD

April

- Minority Health Month

June

- Pride Month: We're teaming up with Cheeky Charity to raise awareness at PRIDE parades. Learn more at CheekyCharity.com
- EAO CRC Think Tank: Continued
An international, virtual event highlighting research for early-age onset colorectal cancer as part of our Path to a Cure

July

- Climb for a Cure: Smoky Mountains

September

- Hispanic Heritage Month

THANK YOU TO OUR BEYOND BLUE SPONSORS!

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**“Our advocacy community is impatient.
They need us to make progress faster.
This is not a passive environment;
it’s an active one.”**

— RICHARD M. GOLDBERG, MD, INTERNATIONAL LEADER IN GASTROINTESTINAL CANCER TREATMENT AND RESEARCH, AND A FIGHT CRC BOARD MEMBER

Your support is essential as we relentlessly fight for informed patient support, impactful policy change, and breakthrough research endeavors.

ONLINE

give.fightcrc.org or email **emily@fightcrc.org**

CHECK

Address your check to “Fight Colorectal Cancer” and mail to 134 Park Central Square #210, Springfield, MO 65806

CALL

(703) 548-1225 x10

STOCK & ESTATE

To learn about setting up estate planning and stock giving, please contact Michell Baker at (703) 407-7534 or **michell@fightcrc.org**

SHOP

shop.fightcrc.org

IN-KIND

To donate products for our events and care packages, contact (703) 548-1225 x17 or email **info@fightcrc.org**.

EMPLOYER MATCHING PROGRAM

Thousands of companies participate in employee matching programs. To learn more about how you can get your employer to match your donation, visit **FightCRC.org/Ways-to-Give**.

Fight Colorectal Cancer is a 501(c)(3) organization and contributions are tax deductible to the extent allowed by law.

Fight Colorectal Cancer has received high rankings for our streamlined, outstanding financial processes from several groups who watch for proper oversight of donations. To view our 990 reports, visit FightCRC.org/Donate



Support the Cause with a **#StrongArmSelfie**

It's easy to show your support for the fight against colorectal cancer.

Flex, snap a pic, and post it along with the hashtag #StrongArmSelfie.

Each post, retweet, or share of a #StrongArmSelfie sends \$1 to Fight CRC!

Tag @FightCRC, so we can share!



Take one and take two! When your husband says we are centered, Wade Knight. Please post your #StrongArmSelfie #coloncancersucks. We need to kick it in the ass and to the curb!



March is Colorectal Cancer Awareness Month, and The Project is participating in the #strongarmselfie campaign to show support for our community of fighters! We invite you to join in on the fun by posting a photo flexing your bicep with the hashtag #strongarmselfie. Each post, retweet, or share sends \$1 to Fight Colorectal Cancer.



My #StrongArmSelfie from the ER



Did you know March is Colorectal Cancer Awareness Month? Colorectal cancer is the second-leading cause of cancer deaths among men and women combined in the United States, and by 2030, it will take more lives of people under 50 than any other cancer. In an effort to raise awareness and support the fight against this aggressive cancer, our GI team is wearing their FIGHT Colorectal Cancer t-shirts every Friday in the month of March. The "strong arm" pose symbolizes the relentless fight against colorectal cancer. You can learn more about colorectal cancer and the effort to fight it via @fightcrc #strongarmselfie



Shout out to my friends @fightcrc on my colonoscopy day



Xavier Noel and his Strong Arm Selfie for Colon Cancer Awareness!! In honor of his Mother @_simplylauren_



@sophiebalzoramd

It's a GI family affair @nyulangone! #DressInBlueDay #strongarmsselfie



@FightCRC

Shout out to our amazing volunteers at the @CBCFInc, #ALC52, @CherylAlston19 and @TappinEllen! Together, they shared their stories and informed conference attendees about #ColorectalCancer screening!



@shannonlizab

Today marks 8 years since being diagnosed with colon cancer. It has been a wild ride.



@TheQueenVee

As a stage IV 20 year #coloncancersurvivor I am very grateful to use my experience to help increase #colorectalcancerawareness & educate people on the importance of #screening!



@cancer_warrior7

striking a #strongarmsselfie for today's colonoscopy!



@jbue1101

By 2030 #ColorectalCancer is projected to be leading cause of cancer deaths for ages 20-49. #UnitedinBlue is a visual reminder there is no time to wait. @agenusbio and @minktherapeutics stand with all relentless champions today, and every day as we seek new treatments for #MSSCRC.



@striveforfiveBC

Me and my dog Pippa both have stage 4 colon cancer and living great lives!

CONNECT WITH US ON SOCIAL MEDIA

 @FightCRC

 **FB GROUP**

ADVOCATES at Fight
Colorectal Cancer

 @fightcrc

 @FightCRC

 Fight Colorectal Cancer

 @fightcrc

FIGHT COLORECTAL CANCER™

SAVE THE BOOTIES



OSTOMY BESTIES SHIRT

SHOP.FIGHTCRC.ORG



BOOTIES MUG

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BOOTY PATTERN SCARF

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 **SCAN HERE**
to shop the look

More info at
SHOP.FIGHTCRC.ORG

