

# BEYOND BLUE

FIGHT COLORECTAL CANCER

VOLUME 18 • ISSUE 1

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



HEALTH  
JUSTICE

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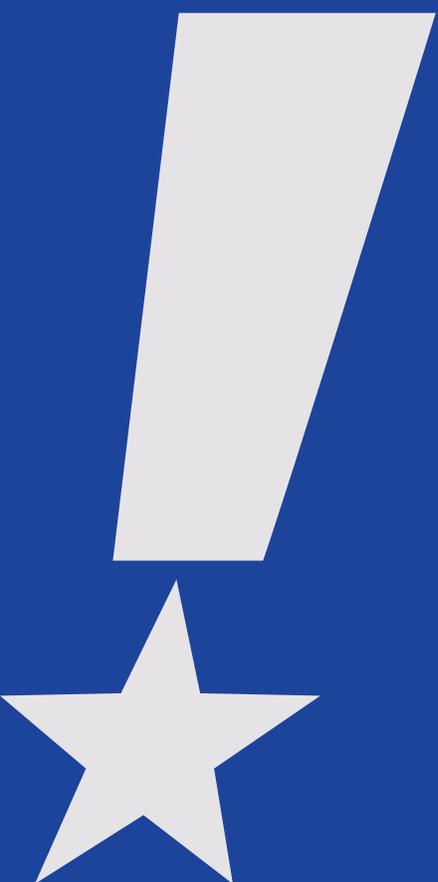
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**We FIGHT to cure**  
**colorectal cancer**  
**and serve as Relentless**  
**Champions of Hope for**  
**all affected by this disease**  
**through informed patient**  
**support, impactful policy**  
**change, and breakthrough**  
**research endeavors.**

*Learn more at [FightCRC.org](https://FightCRC.org)*



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**Jokes**

**What do a clown's farts smell like?**

*They smell funny.*

**Ready for a poop joke?**

*Nope, they stink.*

**I like toilets for two reasons:**

*Number one and number two.*

**How many people does it take to make the bathroom smell?**

*Just a phew.*

Jokes originally posted on fatherly.com.

**SUBMIT A JOKE!**

Email [danielle@fightcrc.org](mailto:danielle@fightcrc.org)

**Word Search**

**FIGHT FOR MORE:** *Health Justice*

T Y F O R E F L E C T D Q I I P K S  
 S S E C C A Y H T A P M E A P U I A  
 O M N J Y G P V Y Y A K J O B T Q I  
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**Comic**



[cancerowl.tumblr.com](http://cancerowl.tumblr.com)

**CANCER OWL** is a creation of stage II survivor Matthew Paul Mewhorter. Visit his work at [cancerowl.com](http://cancerowl.com). Comic reprinted with permission.

**WORD BANK**

- |          |             |           |          |
|----------|-------------|-----------|----------|
| Advocate | Fairness    | Opinion   | Story    |
| Access   | Fight       | Peace     | Strength |
| Believe  | Gaslighting | Prevent   | Trust    |
| Bias     | Health      | Reflect   | Truth    |
| Empathy  | Help        | Represent |          |
| Equality | Justice     | Rights    |          |
| Equity   | Listen      | Screen    |          |



**FOLLOW ANJEE!**

@anjeedavis



## Hijacking Health Equity Isn't OK

I have worked in public health for over two decades now, and I have learned the answers to health care challenges are complex.

A multitude of social factors come into play when health disparities come up: finances, culture, race, sexuality, religion, access to screening and treatment, food, and education. All of these societal factors play a role in patient care.

In 2020, COVID-19 devastated our world. While that was happening, a history of racial bias in the health care system was unearthed. The silver lining was a renewed awareness and attention focused on the ongoing bias, microaggressions, and struggles some patients face.

As the world faced tragedy after tragedy, my own health was impacted by cancer. (Seriously!) My breast cancer diagnosis

during COVID-19 gave me a front row seat to navigating cancer care—already a terrible circumstance—during the worst of circumstances.

**As an Asian American, I experienced bias during my diagnosis and treatment, as some of my questions and concerns were not taken seriously or dismissed completely. But, with decades of advocacy under my belt, I trusted my instincts and rebuilt a team whom I trusted would listen.**

My story is one of thousands that other patients could tell. Anyone who has experienced bias when seeking health care knows the frustration of not being heard, and in a worst-case scenario: What it feels like to slip through the cracks.

Weaving health equity (“health disparities”) and inclusivity efforts into the fabric of our mission is imperative. At Fight CRC, health equity and inclusivity efforts are intertwined across all our programs. We are passionate and committed to health equity because everyone from cities to rural areas deserves the same compassion and care. We consistently strive to improve and amplify our message and reach. We relentlessly fight for ALL patients to have access to care.

In 2020, the awareness for health equity became a genuine wake-up call for many. Some organizations looked inward and assessed if they were reaching communities in need. But other organizations hijacked health equity by benefiting from increased funding without actually using these funds to build programs to positively affect and impact the communities it was meant for.

For me personally, a critical part of health equity is relationship building. Rather than jumping into communities uninvited, there has to be authenticity in how we do the work. When the ingredients of authenticity and commitment are added, we can do our best work by developing innovative strategies to solve the challenges facing health equity and inclusion. It's not fast or easy. It's important not to hijack the process with quick fixes without including the individuals we hope to benefit.

As part of our introspection of 2020, Fight CRC took a step back to assess if we were representing patients of every creed and color. Since colorectal cancer hits racial and ethnic groups hard, we wanted to ensure that all patients were represented when sharing their stories. Some races and ethnic groups see higher incidences and higher mortality rates. We sought out ways to effectively reach these patients.

I am incredibly proud of our team for being intentional and working to improve our health equity efforts at every opportunity possible. Our response to a complicated issue remains consistent: We empower patients; we amplify their stories; and we fight for policy change.

From our research and care teams, and our policymakers, we demand rigor and transparency. We are fighting for equity and access, establishing authentic relationships within the communities we serve. My feet are planted in the ground, enriched by my own personal experiences. Fight CRC is here for the thousands of patients like me who share lived experiences of inequity in health care, and we are committed to see a better future.

We strive to do better because we must do better.

**YOURS IN THE FIGHT,**

**Anjee Davis, MPPA  
FIGHT CRC PRESIDENT**

# Thoughts about our *Fall 2022 Issue:* **THE SURVIVORSHIP MOVEMENT**



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and subscribe.**



**TIM MCDONALD**

*Stage IV Survivor, Florida*

"Even though I provided my answer for the *Bell Ringers* article, I was so interested to read how others felt about it. I haven't had the chance to ring the bell yet, and I may not ever know if it's my last time for chemo, but understanding what it means, and how it can inspire others in the room, is a reason why I will if given the chance."



**PAMELA ALLEN**

*Stage III Survivor, Georgia*

"I enjoyed the entire *Beyond Blue: The Survivorship Movement* issue. I really liked the article *Define Survivor*. Whenever I am honoring and encouraging survivors at awareness events, I get asked the question, 'Am I a survivor if I'm still in treatment?' This article shed light on that conversation for me. I also liked *Bell Ringers*. I thought about how it feels to hear the bell rung knowing that some people may never get to ring it. This literally sent chills down my spine. There is so much thoughtful information in *Beyond Blue*. I enjoyed reading it and sharing it."



**CHERYL ALSTON**

*Stage II Survivor, Maryland*

"There is a lack of resources, information sharing, and screenings in the African American community. *Beyond Blue* is needed here, because there is a fear of having an invasive procedure, of drinking the prep, of finding out if they have cancer and/or polyps. *Beyond Blue* offers understanding of questions to ask; how and why screening works; why early detection is key; who's at risk; and why diet and exercise are important. It offers people time to learn about colorectal cancer on their own, then share concerns or ask questions when they are comfortable."



**RICHARD HAYS**

*Stage II Survivor, Maryland*

"I found the article *Define Survivor* reassuring and hopeful for people diagnosed with cancer. Growing up in the 60s and 70s, people would never say the word 'cancer.' It would be whispered, or called the big 'C' word. And then heads would wag, tears would well up, and people would just assume a death warrant had been issued. There was no help. 'How big is it?' and 'Where is it?' were questions that followed. Thank goodness 'survivor' has replaced these thoughts and beliefs with educated and hopeful family and friends. I much prefer calling myself 'survivor.'"



**DAWN BLATT**

*Stage III Survivor, New York*

"I took the survivorship edition copies to my survivorship appointment at Memorial Sloan Kettering. The nurse practitioner had heard of Fight CRC, and she had positive comments about the organization!"

**Become a Resource Champion in your community.**

You'll receive a **FREE** box of 10 magazines and other resources to distribute.



Sign up at [FightCRC.org/ResourceChampions](https://FightCRC.org/ResourceChampions).

We want to hear from you! What do you think about this issue? Send your feedback to [danielle@fightcrc.org](mailto:danielle@fightcrc.org).

# Locker Rooms & Chemo Chairs

I am a proud Kansas Citian who roots for the KC Chiefs and our star quarterback, Patrick Mahomes. A few years ago after the cultural unrest surrounding George Floyd, Mahomes posted a statement. Part of it read:

“I grew up in a locker room where people from every race, every background and every community came together and became brothers to accomplish a single goal,” he wrote.

Mahomes’ words stuck with me not only because they were a powerful plea for acceptance and unity, but because he articulated something I’ve also experienced. I didn’t grow up in a locker room; instead, I grew up in a chemo chair. At age 17, I was diagnosed with stage III colon cancer and became part of the colorectal cancer community. I quickly realized that cancer was an equalizer. Beating the disease was the singular goal among patients and caregivers. Like a sports team, our similarities connected us. Our differences in age, race, gender, sexuality, religion and ability faded away.

No one fights alone: This is a powerful mantra we rally behind at Fight CRC. This sentiment has gotten me through some hard days. I love that unity is such a strong theme within the cancer community. In fact, this month, we will be on the National Mall for *United in Blue*. Yet something I’ve learned over the years is that in order for true unity to take place, we must connect on similarities and seek to understand and appreciate differences. We all may be Relentless Champions of Hope, but each one of us champions has a unique story.

Some can walk into an ER and get immediate attention, and others get ignored. Some fight to get procedures covered and scheduled on time, while others have no problems at all. Some are represented in medical research, trusting doctors who say they will take good care of them. Others are underrepresented, misunderstood and mistreated—over and over again.

If we’re going to be a voice for change, we must come together under a shared mission. But, our unity will only be as strong as our respect for one another’s stories. As we head into March, Colorectal Cancer Awareness Month, may we stand united in our fight, and may our differences be the sparks that ignite us to keep fighting for more.

**STAY STRONG,**

*Danielle Ripley-Burgess*

**Danielle Ripley-Burgess**  
EDITOR-IN-CHIEF & TWO-TIME SURVIVOR



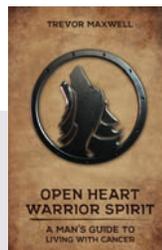
**FOLLOW DANIELLE!**

@DanielleisB



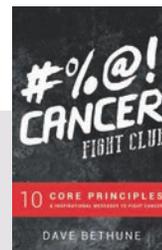
**ABOUT THE EDITOR**

Danielle Ripley-Burgess is a 22-year colorectal cancer survivor first diagnosed at age 17. Today, she’s in remission. Danielle is an award-winning communications professional, author of *Blush: How I Barely Survived 17*, and she serves as Fight CRC’s Chief Storyteller.



**OPEN HEART, WARRIOR SPIRIT: A Man’s Guide to Living with Cancer**

By Trevor Maxwell



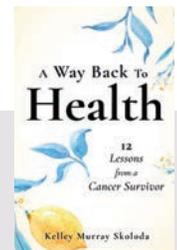
**#%@! CANCER FIGHT CLUB**

By Dave Bethune



**CANCER COULD NEVA: A Motivational Guide to Overcoming Trauma & Illness**

By Kecia Johnson



**A WAY BACK TO HEALTH: 12 Lessons from a Cancer Survivor**

By Kelley Murray Skoloda

**Do you have a book you want us to review or to donate for our Care Packs?**

Email [danielle@fightcrc.org](mailto:danielle@fightcrc.org).

## Book SHELF

**RECOMMENDED READS FOR THOSE FACING Colorectal Cancer**



 **Chad Schrack**

# CHAD *climbed* KILI

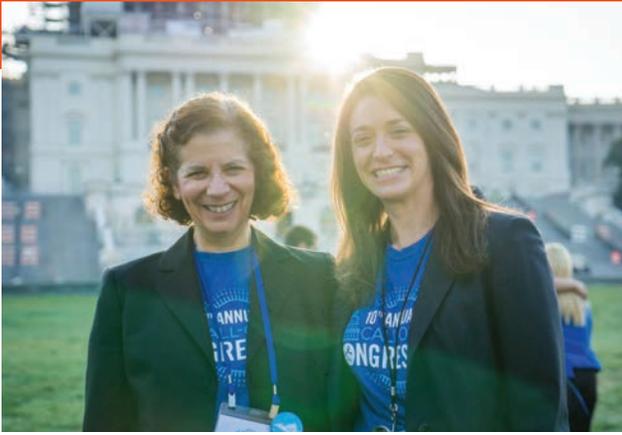
Chad Schrack, an advocate and co-founder of Climb for a Cure, embarked on a major expedition this past fall: He climbed Mount Kilimanjaro (nicknamed "Kili"), the highest single free-standing mountain in the world, for colorectal cancer awareness!

The 19,341 feet high, nine-day climb was one of Schrack's biggest challenges and triumphs. But it certainly wasn't his only. Back in 2018, he took a 2,600-mile, 112-day "Cancer Stroll" across the U.S. Fight CRC's annual Climb for a Cure was inspired by Schrack and his friends' yearly mountain-climbing adventures. The Schrack family hosts an annual "Polar Bear Dip" on New Year's Day, and over the years, they have raised more than \$1 million for Fight CRC.



While climbing Kili, Schrack carried a Fight CRC flag in honor of his wife Sheila, a stage IIIc colon cancer survivor who was diagnosed in 2006 at age 38, and all colorectal cancer survivors from around the world.

**THERE'S NO TELLING WHAT HE WILL COME UP WITH NEXT!**



## Thank you, Dana!

Dana Rye (pictured right) has been an active board member since 2011. With no family history, she was diagnosed with stage II colon cancer at age 24. Dana has led fundraising and advocacy efforts for Fight CRC. She was especially interested in the increasing rate of colon cancer diagnoses in younger patients. As she leaves the Fight CRC board, we want to thank her for everything she has done for our community.



## ADVOCACY VICTORY

Medicare beneficiaries will no longer face out-of-pocket costs for a necessary colonoscopy after a positive noninvasive screening test.

In November 2022, The Centers for Medicare and Medicaid Services (CMS) finalized the proposed rule. Additionally, the rule will lower the minimum age of colorectal cancer screening to 45, consistent with the 2018 American Cancer Society screening guidelines and the 2021 United States Preventive Services Task Force colorectal cancer screening recommendations.

“We are grateful that CMS took this important step to help increase access to colorectal cancer screening and align with guidance released earlier this year by the Departments of Health and Human Services, Treasury and Labor,” said Anjee Davis, MPPA, Fight CRC President. “For years Fight CRC—along with ACS CAN, AGA, and countless other colorectal cancer advocates—have advocated for this necessary policy change. This is an important win for patients.”

Photo source: Getty Images and Instagram



## Celebrities & Colorectal Cancer

We’ve noticed the number of public figures who recently passed from colorectal cancer. Actress Kirstie Alley age 71, Actor Kevin Conroy age 66, Virginia Rep. Donald McEachin age 61, Broadway actor Quentin Oliver Lee age 34, Pelé, the Brazilian soccer legend age 82, and social media influencer Randy Gonzalez from the Enkyboys age 35, to name a few.

We are sending our love to their families, friends, fans, and community members.

Fight CRC isn’t just fighting colorectal cancer. We’re fighting the stigma, confusion, and fear surrounding it. Together with our community of patients, families, and caregivers, Fight CRC works relentlessly to bring attention to colorectal cancer and all the issues surrounding it.

**We recognize and honor the losses we’ve seen from colorectal cancer. These stories drive our passion and mission daily.**

To learn how to honor and remember your loved one alongside Fight CRC, visit our Wall of Champions at [FightCRC.org/Tribute-Wall](https://FightCRC.org/Tribute-Wall).

**HONOR A LOVED ONE**

Visit our Wall of Champions to add a dedication to your loved one.

**HOT** Topic

“YOU PEOPLE DON’T GET THIS DISEASE”

I DON’T

BELIEVE YOU

“IT’S IN your HEA

“you don’t know what you’re talking about”

I’M SURE YOU’RE FINE

# MEDICAL MISTRUST

**Who can we trust? It’s a fair question these days, especially after the past few years.**

**A**s a culture, our trust in government and medical institutions sits at an all-time low. Many patients and caregivers don’t know who to believe, and some have written off doctors all together.

While most patients and caregivers carry some level of mistrust, minority communities are especially vulnerable. But, it’s not without reason. Study after study shows that discrimination, bias and marginalization all play a role in medical mistrust.

It’s not a simple answer when explaining why, but here are a few considerations:

- **History of mistreatment.** See: Tuskegee Syphilis Study, Dr. James Marion Sims, Henrietta Lacks, Americanizing diets in the 1920s.
- **Undertreated.** Many minority patients do not receive empathy or attention when describing pain, especially when compared with white patients.
- **Language barriers.** Patients do not have access to resources in their first languages.
- **Implicit bias:** Health care teams make negative associations with members of a group, usually not realizing it.
- **Inconsistency.** Rotating medical teams who don’t follow patients builds instability and a lack of trust. Some patients lack access to services, or face long delays in care.
- **Misunderstanding and disrespect.** For cultural traditions and approaches to illness.

## **Why Trust Is Important**

Medical mistrust is real, and it’s understandable. Unfortunately, mistrust also leads to poorer outcomes—meaning patients may not respond as well to treatments, and in worst case scenarios, they may not survive their diagnoses.

Withholding critical, personal information from doctors and nurses, and skipping recommended screenings, procedures and treatments, can become a matter of life and death.

*Higher levels of trust are tied to things like better quality of life and improved symptoms.*

## **What Can We Do?**

If you or a family member is struggling with medical mistrust, Fight CRC is here for you. We validate your experience, and we encourage you to self-advocate and not give up. While systemic and structural problems don’t come with simple or easy answers, your health is important.

## **GET A SECOND OPINION**

If you’re not confident in your health care team, or you don’t feel like they’re listening, get a second opinion. Insurance plans should cover second opinion visits, especially if you’ve been diagnosed with colorectal cancer and you’re seeking a surgeon, oncologist and/or radiologist. If you need help finding a provider, use Fight CRC’s Provider Finder, which will generate a list of physicians who are treating high volumes of patients with colorectal cancer. Access it at [ProviderFinder.FightCRC.org](https://www.fightcancer.org/provider-finder)

## **GET MEDICALLY REVIEWED RESOURCES**

Medical experts review all of Fight CRC’s brochures, mini magazines, videos and online content. Additionally, diverse focus groups consisting of patients and caregivers review our printed materials and provide feedback for our blogs. We have Spanish resources available now, and more translations to come in 2023. Visit [FightCRC.org/Resources](https://www.fightcancer.org/resources).

If you’re looking for a specific topic or need a resource translated in a certain language, please contact our team at [patientinfo@fightcancer.org](mailto:patientinfo@fightcancer.org).

## **WORK WITH OUR PARTNER GROUPS**

If you are part of a community that has experienced marginalization, bias and discrimination in health care, please reach out to our partners for resources and advice. They are in the trenches and building tailored tools to help you and your family.

### Sources

- [www.medicalnewstoday.com/articles/medical-mistrust-linked-to-race-ethnicity-and-discrimination#Mistrust-and-health-discrimination](https://www.medicalnewstoday.com/articles/medical-mistrust-linked-to-race-ethnicity-and-discrimination#Mistrust-and-health-discrimination)
- [www.ajmc.com/view/5-things-about-medical-mistrust](https://www.ajmc.com/view/5-things-about-medical-mistrust)
- [onlinelibrary.wiley.com/doi/10.1002/hast.1080](https://onlinelibrary.wiley.com/doi/10.1002/hast.1080)
- [pubmed.ncbi.nlm.nih.gov/10477478/](https://pubmed.ncbi.nlm.nih.gov/10477478/)

## ***FIGHT* COLORECTAL CANCER**

**Fight CRC partners with the following groups who provide critical resources and support to the patients and caregivers they serve.**



American Indian Cancer  
Foundation  
[americanindiancancer.org](http://americanindiancancer.org)



Asian American Cancer  
Support Network  
[aacsn.org](http://aacsn.org)



The Association of Black  
Gastroenterologists and  
Hepatologists (ABGH)  
[blackgastro.org](http://blackgastro.org)



Blue Hat Foundation  
[thebluehatfoundation.org](http://thebluehatfoundation.org)



National LGBT  
Cancer Network  
[cancer-network.org](http://cancer-network.org)



Salud America  
[salud-america.org](http://salud-america.org)

# BELIEVE

*Us*



By **DANIELLE  
RIPLEY-BURGESS**

**The doctor took one look at her, sized her up and down, and then dismissed what she'd come into his office about.**

**F**or years, Amanda Lee, a 27-year-old from Los Angeles had seen blood in her stool, which was mistaken for hemorrhoids. But an unexplained drop

in weight and major lower abdominal cramping gave her red flags. She struggled to eat anything outside of purees, and her pain was increasing by the day. Three prior visits to the ER led her to believe she had irritable bowel syndrome (IBS), and she needed to take laxatives. They weren't working.

After fighting for an appointment with a gastroenterologist, she left sorely disappointed, body-shamed and in tears.

"He said, 'Maybe that's not such a bad thing' that I couldn't eat because of my pain," she told *People Magazine*. "He was praising the fact that I was not eating."

From the driver's seat of her car, she immediately posted an emotional TikTok video about the appointment, something she now considers lifesaving.

TikTok viewers urged her to find another doctor who would take her symptoms seriously. She followed their advice.

"I found Dr. Tahmina Haq after hours of searching, and she was worth every minute because she saved my life," Lee said.

**"IF YOU FEEL LIKE YOUR DOCTOR IS NOT LISTENING TO YOU, TRUST ME WHEN I SAY THERE IS SOMEONE OUT THERE WHO WILL. YOU ARE NOT ALONE."**

Dr. Haq did a colonoscopy and discovered stage IIIa colon cancer.

Lee found a reliable oncology team who started her on chemotherapy, and she had surgery to remove the tumor. Her growing social media audience tuned in to follow her prognosis, and her story went viral, catching the attention of outlets like *People Magazine*, *BuzzFeed*, *Today*, and *Insider*.

"After my story went viral, I felt like the woman I was supposed to be all my life was unlocked and unleashed," Lee said. "The public speaking side of me stepped out, and I never want to stop telling my story and other people's stories."

Today, Lee continues to vulnerably engage with social media audiences. She hasn't only

put a spotlight on the alarming rates of colorectal cancer happening in young adults, but on another situation many patients, especially females, face: medical gaslighting.



These days, most people have heard of the word **"gaslighting."**

It was so popular in 2022, Merriam-Webster Dictionary named it the word of the year. The term, which at its most basic form means misleading someone to take personal advantage, has many contexts, including psychological and political. In a March 2022 article, *The New York Times* acknowledged the term can also be medical. They wrote:

**"Patients who have felt that their symptoms were inappropriately dismissed as minor or primarily psychological by doctors are using the term 'medical gaslighting' to describe their experiences and sharing their stories."**

It's an appropriate term to explain many of the stories Fight CRC hears every day.

"I had to push back on my physician who did not want to prescribe a colonoscopy," said Fight CRC Ambassador Alejandro Potes. "I was diagnosed at the age of 34 with stage II colorectal cancer. Pushing to get screened saved my life."

Potes was gaslighted due to his age. Another Fight CRC Ambassador, Paula Chambers Raney was gaslighted due to her race and sexuality.

"When I would say I was in pain, especially with colorectal cancer, some providers would say, 'You people can take pain. Come on, toughen up! Just blatant inappropriate things. [There was also] a doctor who sat me down and told me straight up, 'I think you're going to hell. I can't treat you.' I said, 'Thank you for telling me. I don't want you to treat me.'"

*Continued on page 14*

# CHAMPION *Stories*

Several of our Relentless Champions have experienced dismissal from doctors and delays in care. Read what happened, and their advice to other patients who they hope can avoid the same thing:



## Lisette Caesar

"For months I was misdiagnosed with diverticulitis. Doctors realized I had cancer on the operating table."



## Tracy Ten

"I met with a gastroenterologist that brushed off my symptoms and said I needed to change my diet. According to the doctor, I was

severely constipated, and I was sent home."



## Scott Hancock

"In May 2018, I began to have pain in my right side. My general practitioner thought that maybe it was gas, or

possibly a gallbladder issue, or something related. Three months later, I had a colonoscopy and was told I had stage IV colon cancer."



## Kecia Johnson

"I had been walking around for months in massive pain and told I simply had a hemorrhoid, or I was having side effects

from just having battled COVID-19."



## READ *their* STORIES

Scan to visit our Champion Stories hub where you can read these patients' stories and others like them.

Continued from page 13

This is part of the story Chambers Raney, a stage I patient diagnosed at age 44, told the National LGBT Cancer Network. As a gay, Black woman, she faced many barriers to care in the years she suffered from chronic pain and colorectal cancer symptoms: delayed visits, lack of consistent care providers, pain not taken seriously, long ER wait times, misdiagnosis. She saw over 20 medical doctors, nurse practitioners, and ER doctors in a 14-month period. They cycled through the community clinics she was visiting, due to losing her job, thus her health insurance, and not being able to qualify for benefits under her wife's insurance plan since her state didn't recognize their marriage.

*Fortunately, a doctor finally took her seriously and performed a colonoscopy that discovered her tumor, and she's now an emboldened advocate for patients in similar situations.*



Age, gender, race, sexuality, religion and nationality are some of the most common reasons patients face medical gaslighting. Sometimes, patients who lack health literacy or self-advocacy may struggle to get adequate care. But, this isn't always the case.

Anna Payne was an experienced patient, having been diagnosed with cystic fibrosis (CF) at a young age. She had been in and out of doctor's offices, on and off medicines, for her whole life. Thanks to the drug TriKafta®, she felt like her "death sentence had been turned into a chronic illness that can be managed with medications and treatments." She'd learned how to listen to and closely watch her body.

That's why when she felt a mass, she alerted her doctors and asked for it to be biopsied.

"I sensed something was wrong over the summer, because of intuition more than symptoms," she said. "Four more days went by before the doctors biopsied the groin mass, something I asked for

on the second day. At first, the doctors seemed to dismiss the idea, thinking I was too young."

Unfortunately, her intuition was right and the digestive issues she'd begun experiencing were not tied to CF, like some assumed, but they were from the stage IV colorectal cancer that had grown into her liver, ovaries, and lymph nodes. She now implores patients to not ignore their symptoms and push to be seen.

"Be your own vociferous advocate," she said. "I'm 34 right now and am living in a world of uncertainty. There's no set plan, timeline, end date, or outcome for me. But every day I'll get up and live here, regardless of what gets thrown at me. I'll learn to be comfortable living in the uncomfortable."



"For 34 years, I've choked down close to 50 pills as part of a daily regimen to manage my cystic fibrosis. But the one bitter pill I wasn't prepared to swallow was when I was told, 'You have stage IV colon cancer.'"

—ANNA PAYNE

Medical gaslighting is not found in every patient story. Amongst our diverse collection of champion stories, the majority of patients and caregivers say they got prompt medical attention when something was wrong. Their ER visit led to the right scans and a quick diagnosis; medical teams took their symptoms and pain levels seriously. Insurance covered the tests, the wait times were reasonable, and follow-ups were run. This is how it "should" go in an ideal world. When the system is working, it saves lives.

But unfortunately, the system isn't working for *every* patient *every* day. Medical negligence has led to failures in health care, late-stage diseases, diagnoses, and patient deaths.

**Gaslighting isn't just a cultural buzzword this year, it's a critical issue that must be addressed. In the fight for more health justice, we must start with this: Patients must be believed.**

# WHERE are they NOW?



**Amanda Lee**

Amanda is currently a model and in remission. She's dedicated to sharing humor, body positivity and colorectal cancer awareness with her thousands of followers on TikTok and Instagram.



**Paula Chambers Raney**

Learning how to self-advocate lit her fire for activism. She became an election judge, and she recently joined Fight CRC as the Hope Coordinator.



**Alejandro Potes**

Alejandro served as a Fight CRC Ambassador in 2019, and today he continues to urge young people, especially Latinos, to get screened.



**Anna Payne**

Understanding the heightened risk of colorectal cancer amongst patients with chronic illnesses, she has made it her mission to speak out and insist that patients get screened at earlier ages.



**Uncomfortable With Your Doctor?**

Use Fight CRC's Provider Finder to find a new one. Our database will show physicians based on the number of patients they see with colorectal cancer and how involved they are in the scientific community.



**Kentisha Mazeke**

"For years, my mother, Felita Rollins, was dealing with blood in her stool and stomach cramps. She was misdiagnosed with IBS and hemorrhoids. She listened to her doctors; why wouldn't she? They're the experts. If she would have advocated for her own health, she may have had more time...In my case, I was told by my primary doctor I didn't need screenings until I was 40. When I turned 35, I got my own gastro doctor to build a relationship, and he told me I was late for my colon exam due to my mom's history. I was upset: Here I was being like my mother, taking measures to be proactive about my health, and I was given misinformation. Insurance denied covering the test, and I had to fight to get it."



**Sara McLean**

"I kept notifying my family doctor that I had blood in the toilet coming from my bowels as if I was on my period. He stated it was hemorrhoids."



**Ivette Moya**

"My husband took me to the hospital I usually went to and was told that I had a small ruptured ovarian cyst and I was impacted. They sent me home with Vicodin® that didn't help, without flushing me, without a CT scan. They told me to see my GYN on my next visit."



**Esteban Garcia**

"At my physical, my doctor said occasional blood when going to the bathroom could be a number of things, and that he wasn't too concerned. I insisted on being referred to a gastroenterologist because my step-father had been diagnosed with stage IV colon cancer. I couldn't get an appointment for almost three months."



**Phuong Gallagher**

"When I started experiencing violent and excruciating stomach pains in 2006, my doctor did not think cancer could be the cause—I was too young. I was told it was likely IBS and to switch to a bland diet."

2023 **AMBASSADORS**

**Ambassadors are volunteers who put a face to colorectal cancer and advocate for our mission all year long. Meet our 2023 Ambassadors!**



**Pam Allen**  
 "I fight for a future free of colon cancer so that my grandchildren and others can enjoy and live life to the fullest."  
**STAGE III SURVIVOR**  
*Elberton, GA*  
**ENTERED THE FIGHT:**  
 6/30/12, Age 50  
 mellajames6



**Christi Andringa**  
 "I fight for awareness, saving lives, creating hope, finding light and love in the midst of a heart-breaking battle. I fight for every family that I can touch in some way to make the journey easier."  
**CAREGIVER**  
*Edina, MN*  
**ENTERED THE FIGHT:**  
 Christi's husband, Rob, was diagnosed on 12/15/17 at age 49.  
 christiandringa



**Sarah Broadus**  
 "I fight for a chance to dance with my son at his wedding, to watch my daughters change the world, and to be present with their milestones."  
**STAGE IV SURVIVOR**  
*Woodstock, GA*  
**ENTERED THE FIGHT:**  
 5/14/21, Age 36  
 thebroadusbunch   
 sarahbroadus



**Christine Bronstein**  
 "I fight to break the stigma around colorectal cancer. People are not comfortable talking about buttholes or butts or rectums or poop...making people feel more comfortable talking about their butts and their guts could save lives."  
**STAGE III SURVIVOR**  
*Kula, HI*  
**ENTERED THE FIGHT:**  
 2/21, Age 48  
 chrisbronstein



**Michael Holtz**  
 "I fight for myself and to prevent other people from going through what I did. My dream is to end cancer as we know it."  
**STAGE III SURVIVOR**  
*Knoxville, TN*  
**ENTERED THE FIGHT:**  
 3/27/12, Age 43  
 michaelholtzonline   
 michaelholtz



**Meredith Huetter**  
 "I fight for my young son, so he does not battle this terrible disease. I fight to reduce the number of us impacted by colorectal cancer. I fight to remove the stigma of those living with an ostomy, like me."  
**STAGE III SURVIVOR**  
*Santa Rosa, CA*  
**ENTERED THE FIGHT:**  
 12/7/20, Age 46  
 mama\_has\_a\_stoma



**Denise Johnson**  
 "I fight in honor of my daughter who was taken too soon."  
**CAREGIVER**  
*Gaithersburg, MD*  
**ENTERED THE FIGHT:**  
 Denise's daughter, Lauren, was diagnosed on 7/25/17 at age 25.  
 dedeej5 mizdee



**Kecia Johnson**  
 "I fight for my purpose that I know has been already set out and formatted for me, as well as my amazing little girl who looks at me every day and reminds me just why I was chosen to be her mommy!"  
**STAGE IV SURVIVOR**  
*Houston, TX*  
**ENTERED THE FIGHT:**  
 8/6/20, Age 36  
 iamkeciaj

2023

# FIGHTCRC AMBASSADORS



### Catherine Martin

"I fight for everyone who said they were 'too young' for colorectal cancer."

#### STAGE IV SURVIVOR

Clayton, MO

#### ENTERED THE FIGHT:

12/13/19, Age 47

catpartdeux kitty7536



### Mark Moore

"I fight for those who are going through treatment right now. I am also fighting to educate individuals on the importance of getting screened for colorectal cancer."

#### STAGE I SURVIVOR

Durham, NC

#### ENTERED THE FIGHT:

5/11/20, Age 50

coldblue2000

bicmark2000



### Carol Rivera

"I fight to support the CRC patients and caregivers, and to make sure whoever is fighting this disease knows they are not alone."

#### STAGE IV SURVIVOR

Carolina, Puerto Rico

#### ENTERED THE FIGHT:

2/11/21, Age 42

carola\_333

carolriveramar1



### Erin Verscheure

"I fight for the people who did not have the opportunity to share their story and for the people who need a voice when they are not heard."

#### STAGE IV SURVIVOR

Clinton Township, MI

#### ENTERED THE FIGHT:

8/31/16, Age 18

erin\_verscheure

erinverscheure



### Ryan Vieth

"I fight for myself, my family, and for everyone who is battling or impacted by this disease! I want to encourage and help anyone I can to be able to live an unforgettable life even through this battle."

#### STAGE III SURVIVOR

Centennial, CO

#### ENTERED THE FIGHT:

9/12/19, Age 47

cocancerwarrior

ryanvieth



### Ruth Savard

"I fight for a brighter, cancer-free future."

#### STAGE IV SURVIVOR

Sun Prairie, WI

#### ENTERED THE FIGHT:

5/3/19, Age 40

revanlan



### Michael Stern

"I fight for myself, my family, my friends, and everyone who is touched by cancer."

#### STAGE IV SURVIVOR

Aventura, FL

#### ENTERED THE FIGHT:

10/18/19, Age 52

michaelsventura

Interested in becoming a 2024 Fight CRC Ambassador?

APPLICATIONS OPEN IN MAY.





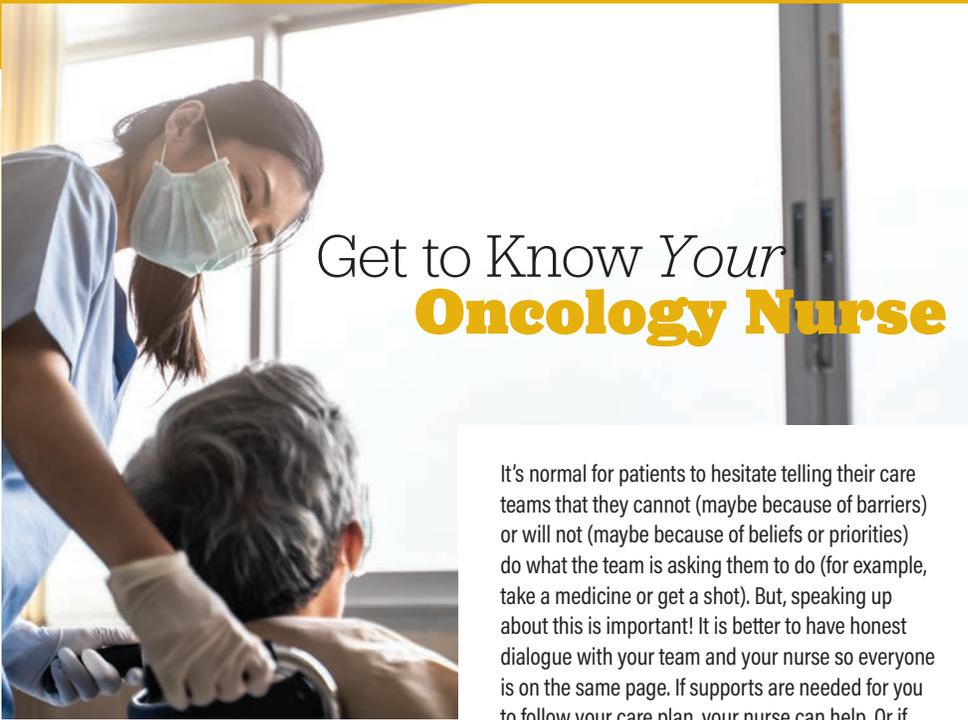
## HONORING THE FIGHT OF ***“The Flying Greek”***

*“Colorectal cancer didn’t stop him from sharing his love for life. He was brave, strong, and committed to helping others.”*

— ANJEE DAVIS, MPPA, PRESIDENT OF FIGHT COLORECTAL CANCER



SCAN TO READ MANOLI’S STORY AND FIND OUT IF YOU NEED TO BE SCREENED.



## Get to Know Your **Oncology Nurse**

Year after year, nursing ranks as the most trusted profession in the Gallup Poll.

If you've been a cancer patient for more than a day, you've probably learned why that is. Nurses play an important, critical role in cancer care. We talked with Mihkai Wickline, MN, RN, AOCN, BMTCN, who is a longtime oncology nurse, about why the nurse-patient relationship is so important.

### **Q** Why should patients consider opening up to their nurses?

**A** Nurses exist to serve the patients under their care. Nurses want to understand patients as whole people, and they care about more than just the disease or the symptoms the patient is experiencing. Nurses need to know what patients are going through so they can help them plan the best care that takes everything into account. This means being honest about what is going on with all aspects of your life.

When patients are honest with their nurses, it allows the nurses to take better care of them. This doesn't only apply to the physical or emotional concerns, but the spiritual, relational, financial, recreational, and vocational concerns too.



### **MIHKAI WICKLINE, MN, RN, AOCN, BMTCN**

A longtime oncology and bone marrow transplant nurse and a PhD candidate in Nursing Science. Additionally, she has dabbled in teaching undergraduate nursing and working with people victimized by the sex trade.

It's normal for patients to hesitate telling their care teams that they cannot (maybe because of barriers) or will not (maybe because of beliefs or priorities) do what the team is asking them to do (for example, take a medicine or get a shot). But, speaking up about this is important! It is better to have honest dialogue with your team and your nurse so everyone is on the same page. If supports are needed for you to follow your care plan, your nurse can help. Or if your care plan needs to be modified to better fit your needs, your nurse can help.

### **Q** How can oncology nurses uniquely advocate for their patients?

**A** Oncology nurses have experience advocating for patients. We help advocate both within the multidisciplinary team and outside of the health care team (for example with schools, employers, insurance companies) to ensure all avenues are explored so the patient and family get what is needed. Nurses are an important, respected member of the care team and can use their experiences and their voices to ensure the patient's needs are being met. If you are frustrated by "dead ends" when you try to get what you need during your cancer experience, ask your nurse to help.

### **Q** What benefits have you seen from patients building a trusted relationship with their nurses?

**A** The patient's experience is richer, and the nurse's job is more fulfilling. A trusted relationship between nurse and patient borders on the sacred...the connection between nurse and patient is more than a sum of its parts, but becomes a third entity that is a force for healing and growth.



### **We're just people taking care of people.**

Doctors aren't omnipotent, and nurses aren't perfect. But, we want to do our best and see our patients' humanity in front of us.

*Mihkai Wickline*



### **Q** You talk about "bearing witness." What is that, and what should patients know?

**A** One of the privileges of being a cancer nurse is bearing witness to our patients' lives.

Bearing witness involves attesting to the authenticity of the patient's experience by being fully present and listening to their story—both the said and the unsaid—and being able to reflect this narrative back to them in a way that promotes healing in their circumstances. Cancer is tough, but having a nurse who understands what you are experiencing and demonstrating through their words and actions that you are seen and your experience matters can be validating. Entering a patient's narrative during their cancer experience is one of the most fulfilling aspects of being an oncology nurse, and bearing witness is an intentional practice to honor this gift.

### **Q** If a patient is struggling to open up, what are some conversation starter ideas?

**A** Tell your nurse something about yourself that has nothing to do with why you're there that day. If you're brave enough to open the door, share your greatest joy, or your biggest worry. Start somewhere.

With a nursing relationship, you go deep fast, at least physically. You're forced into this intimate relationship that you never wanted in the first place. Any time an oncology nurse is needed, it's a horrible circumstance. But, if you can, try to invite your nurse to see you as a person by sharing something about your life. Nurses are there to listen without judgment. We've heard it all, and we're open to anything. There's nothing that's going to shock us.

### **DID YOU KNOW?**

Oncology nurses undergo special training. If your nurse has OCN or AOCN behind their name, it means they're a certified nurse who has gone above and beyond to grow their body of knowledge, and they offer specialized oncology care.



# Screen at Home

By  
**THERESA MASCHKE**

Did you know  
you can screen  
for colorectal  
cancer at home?

Most people think of colonoscopy when talking about colorectal cancer screening, but there is another option available to some people: at-home tests. These tests are FDA-approved, and they are a good option for adults 45 or older who'd rather screen in the privacy of their own homes and for people who aren't experiencing any signs or symptoms.

**If you're  
passionate about  
getting people  
in your life  
screened, share  
this information  
with them!**

## TYPES OF AT-HOME TESTS

These tests are also called “stool tests,” and patients collect stool samples using a kit. In general, FIT-fecal DNA (Cologuard®) will detect nine out of 10 cancers as a single-time test. FIT will detect eight out of 10 cancers.

At-home colon cancer tests are not like colonoscopies, which need to be repeated every 10 years (sooner if your doctor recommends, or if you show signs and symptoms of colorectal cancer). At-home colorectal cancer screening tests require more frequency than colonoscopies do.

### **FIT-DNA (for example, Cologuard®)**

- A stool DNA test looks for abnormal sections of DNA. Additionally, a FIT-DNA looks for blood in your poop.
- One stool sample is needed.
- This test is repeated every three years. An abnormal test does not necessarily mean you have cancer, but it requires a follow-up colonoscopy to determine why the test is abnormal.

### **Fecal Immunochemical Test (FIT)**

- The FIT can identify blood in poop that is microscopic or otherwise difficult for you to see.
- One stool sample is sufficient.
- This test is repeated every year. An abnormal test does not necessarily mean you have cancer, but it requires a follow-up colonoscopy to determine why the test is abnormal.

## DOES INSURANCE COVER THESE TESTS?

First, it's important to be aware that insurance does not necessarily cover both the FIT-DNA and FIT. Many do, but some don't. Be sure to call or contact your insurance company to find out which test(s) they cover. Your out-of-pocket costs may differ depending on which test you take. It's important also to choose the test that is most affordable to you, that's in agreement with your doctor's recommendations.

An at-home test from a drug store may work, but we strongly recommend you obtain the test from your doctor, or with his or her knowledge. We understand that it may be more convenient and cost effective for you to buy and take the test on your own, but there is so much misleading and misinformation out there, working closely with your doctor is the best step.

## WHAT IF THE TEST IS POSITIVE?

Sometimes an at-home colorectal cancer test shows a positive result. This does not always mean you have cancer. However, it is vital that you treat a positive result urgently.

You will need to have a follow-up colonoscopy. Do not skip this step. Be sure to schedule this as soon as possible.

## WHAT IF THE TEST IS NEGATIVE?

If the test is negative, that means nothing appears to be abnormal. You will need to repeat the test in the future. Generally, take a FIT-fecal DNA (Cologuard) follow-up test every three years. A FIT should be repeated annually.

**Worth Noting:** These tests may not detect colon polyps as a colonoscopy does. It may take years for polyps to grow, and nearly all colon cancers or rectal cancers start as polyps.

## WHEN IS THIS NOT AN OPTION?

An at-home test does not explain what the cause of bleeding is or why you have blood in your stool.

## The purpose of at-home tests is to check for cancer in people who do not show signs or symptoms and who are at the colorectal cancer screening age.

Furthermore, if you have a family history of colon cancer or rectal cancer, or if you have a personal history of inflammatory bowel disease, it's important to get a colonoscopy rather than take an at-home test.



## YLA'S STORY

"A simple Cologuard® test—that was the beginning of my journey. My doctor recommended it during a visit at the beginning of 2020, which was also the beginning of COVID-19. I had no symptoms, so I had no reason to fear, or so I thought. You can imagine my shock when I received a call saying I had a positive result. On March 19, I had my first colonoscopy ever and one week later, I was in surgery. I was diagnosed with stage III colon cancer. You never think it's going to be you."

—Yla Flores



## FINAL RECOMMENDATIONS

An at-home colorectal cancer test is the best test option when compared with not having your colorectal cancer screening. This is a reliable option for many people. Be sure to take your stool test consistently. Take one as often as your doctor recommends.



SCAN

Read more FAQ about At-Home Tests vs Colonoscopy.



+ RESOURCES TO COMBAT THEM !

# 1 ENGLISH-ONLY RESOURCES

Not having brochures and websites that are written in your first language is a barrier for many non-English speaking patients and caregivers. Many efforts are underway to translate resources into Spanish, Chinese, and other common languages spoken in the U.S. You can also ask your hospital for a medical translator or social worker, and they can help you know what's available in your area.

Looking for translated health resources?

 Try [healthinfotranslations.org](http://healthinfotranslations.org)

# 2 A PLACE TO STAY

Many patients must travel away from home for doctors appointments, second opinions, scans, treatment and clinical trials. There are several programs that either offer a reduced rate for lodging or a free place to stay.

Check out these resources:

-  [hhnetwork.org](http://hhnetwork.org)
- [joeshouse.org/resources](http://joeshouse.org/resources)
- [rmhc.org](http://rmhc.org)

# 3 CAN'T LEAVE THE HOUSE

Colorectal cancer patients have many reasons to stay home. They may be recovering from surgery, struggling with an ostomy, or in pain due to LARS. Many patients on treatment are immunocompromised and must limit exposure to viruses. For patients with treatment side effects like neuropathy, skin toxicity and radiation burns, they'd much rather stay at home than go out. Ask your team and insurance company about home health options—care where the teams come to you. Also, telehealth may be an option for you to connect with your doctor from the privacy of your home. (You'll need Wi-Fi for telehealth!)

Read up on telehealth:

-  [fightcrc.org/telehealth](http://fightcrc.org/telehealth)

# 4 A RIDE

A ride—or a flight—to treatment is a real need for some patients. Don't let a lack of transportation prohibit you from getting the care you need. There are several programs around the country offering rides and flights for patients.

Here are a few places to start:

-  [chemocars.org](http://chemocars.org)
- [aircarealliance.org](http://aircarealliance.org)
- [mercymedical.org](http://mercymedical.org)

**Do not be scared to ask for resources in your first or native language! It is so important for you and your family to fully understand what is going on; that's the key to informed consent. If you are receiving services from a facility that is currently accepting federal funding, it is your right to be provided with translated materials by your medical team. It never hurts to ask!**

**ALEX HERNANDEZ**

Freelance Spanish Interpreter/Translator,  
Certified Health Care Interpreter (CHI-Spanish)



## 5 EMPTY PANTRY

Food insecurity—not having enough to eat—is more common than you might think, especially amongst cancer patients. Colorectal cancer patients especially may struggle with affording or finding foods they can eat. See page 26 for more information and how to get help.

## 6 FEELING ALONE

Support is critical when you're fighting cancer. When you struggle to lift yourself up, a community should be there to come alongside you. Finding "your tribe" can make all the difference, and it's a critical step to fighting colorectal cancer. If you're looking for community, here are a few places to start:

### Local groups

Ask your nurse or social worker if your hospital offers any support groups.

Search [cancersupportcommunity.org](http://cancersupportcommunity.org) to see if a group is in your area.

### Online

Check out Fight CRC's Community of Champions or Facebook groups.

Newly Diagnosed? Come to our Resource Meetups (see page 32 for details)!

## 7 EDUCATION AND EMPLOYMENT

Education, in general, is tied to better health outcomes. If you're able to work, a job providing income and routine—which often brings purpose and stability—can be essential during your cancer fight.

For resources involving education and employment, check out:

 [cancerandcareers.org](http://cancerandcareers.org)

## 8 UNINSURED

If you don't have insurance, or enough insurance, you're not alone. Many patients have been in your spot.

Here are a few organizations to reach out to for help:

 [cancercaare.org](http://cancercaare.org)  
[patientadvocate.org](http://patientadvocate.org)  
[trriagecancer.org](http://trriagecancer.org)

## 9 FEELING DOWN

In a March 2022 article in *The New York Times*, it was reported that cancer patients are at a higher risk of depression and suicide, and that the "suicide rate was 85 percent higher for people with cancer than the general population." If you're feeling blue, please reach out to someone on your health care team and ask about therapy resources.

Need a counselor? VeryWell Health deemed TalkSpace to be the best overall online counseling service for cancer patients.



SCAN

Scan to read what other mental health resources made VeryWell Health's list.

## 10 STRUGGLING TO PAY FOR CANCER

Many patients struggle with the financial impact of cancer. Out of all barriers, this is one of the most common, as it affects patients of every age, race, and background. There are a few things to consider if a financial burden is a barrier in your cancer fight:

### Social Security programs

Social Security Disability Insurance (SSDI) and Supplemental Security Insurance (SSI) are both programs through the federal Social Security program. There may be multiple steps involved; however, if you're considered disabled or terminal based on your cancer diagnosis, these programs may be an option for you.

If you apply and are rejected, don't despair. Approximately two-thirds of applicants are denied SSDI the first time they apply. Either apply again or consider finding an attorney to help you. Many states have pro bono attorneys who will assist you at no charge.

### Cancer funds

Many grants and funds exist to help cancer patients. Ask your nurse or social worker about local resources. There are also funds that are available to patients nationwide.

For a start on how to find them, check out:

 [fundfinder.panfoundation.org](http://fundfinder.panfoundation.org)  
[cancerfac.org](http://cancerfac.org)

## A ONE-STOP SHOP

When it comes to finding resources for cancer patients, the American Cancer Society (ACS) has a lot to offer. ACS helps patients all across the United States.

Scan these QR codes to access ACS's resources:



← [Transportation](#)



← [Translated Resources](#)



← [Financial Support](#)



← [Lodging](#)





## We're **HERE** FOR PATIENTS

I joined Fight Colorectal Cancer in August 2022 as the Patient Education and Research Program Manager.

I have spent the past 20 years working in hospital and clinic settings, and I am excited to use that experience and what I learned to help patients and caregivers get the information and resources they need to navigate their fight with colorectal cancer. Fight CRC has a wide array of programs and resources that help people prevent colorectal cancer, find it early, and locate treatment and support when they need it.

We publish a suite of free printed brochures and resources designed to educate and inform patients on a variety of topics, including screening, biomarkers, clinical trials, surgical options, among many others. These resources are regularly reviewed and updated to provide the most current information, and are all medically reviewed by experts in the field. We work to get these resources into the community by providing them to our Resource Champions, advocates, doctors and clinics, and anyone else who requests them, to increase awareness of colorectal cancer and give insight into their

diagnosis. We also offer these publications in digital formats on our website, completely free to anyone who requests them.

In order to help patients get the absolute best care possible, Fight CRC has created an online Provider Finder and a Clinical Trial Finder. The Provider Finder helps patients locate and contact gastroenterologists, oncologists, surgeons and other physicians in their area that specialize in treating colorectal cancer. The finder also indicates which physicians are more likely to do tumor biomarker testing, and who has experience with clinical trials. The Clinical Trial Finder is a curated database of colorectal cancer-specific clinical trials to help those looking for a clinical trial find one that meets their needs.

A variety of virtual support and educational services are also available through our website, Instagram, Twitter, and Facebook. We host biweekly "Resource Meetups" via Zoom, to help those impacted by colorectal cancer find peer-to-peer support and direct them to educational resources. Anyone impacted by colorectal cancer is welcome to join! Fight CRC routinely presents educational webinars, hosted by various experts in the field, to provide timely, thorough and in-depth information about different topics, such as colorectal cancer surgical options.

Through our Research Advocacy Training and Support (RATS) program, we strive to bring the patient voice to the clinical research space. Our RATS are volunteer advocates who undergo extensive training to learn more about colorectal cancer research across the continuum and actively participate in academic and industry settings to improve and advance the science around colorectal cancer research.

No one fights colorectal cancer alone, and Fight CRC is proud to actively collaborate and partner with a wide range of organizations dedicated to supporting patients and ending this disease. Through these partnerships, we are able to extend our reach and address needs that may otherwise be missed by a single organization.

**There is no "one size fits all" approach to colorectal cancer prevention, treatment, and survival, and collaborations with our partners help to improve outcomes for those who most need our support—patients, caregivers, and their families.**

There is so much work to be done, and I am proud to be part of an organization that takes its mission so seriously.

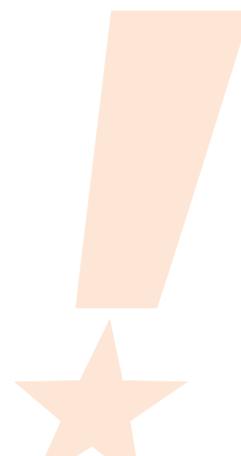
If you need any resources or support as you navigate your way through this disease, please don't hesitate to reach out.

ZAC GETTY

*is Fight CRC's Program  
Manager of Patient  
Education and Research*

**FOLLOW FIGHT CRC  
FOR RESOURCES!**

@FightCRC





# Finding *my* Place on the Path

By **WENORA JOHNSON**

**Five years ago, after completing treatment for colon cancer and battling another cancer afterward, I had no idea I would become a fierce research advocate.**

Fierce is the perfect word to describe how I felt after being diagnosed with a third cancer and finding out I'm Lynch syndrome positive; I realized that my voice was incredibly important.

Knowing I would need the best treatment options in the event of a future cancer diagnosis, I began my advocacy journey by communicating with my health care provider and team about my concerns, future cancer care, and where I could make a difference in other patients' lives. This led me to Fight CRC.

I first got involved with Fight CRC through sharing my story on the website and by attending Call-on Congress. Soon after, I became a research advocate with Fight CRC, which led to becoming a Clinical Trial Curator. This helped me understand the importance of various treatment options that are still in clinical trials that could possibly save my life. From here, my opportunities have grown.

I've served in many research roles, including being a consumer reviewer for the Department of Defense; PCORI Ambassador; Cancer Policy and Advocacy Team member for the National Coalition for Cancer Survivorship; and participant in the American Association for Cancer Research's Scientist Survivor Program.

I've attended research conferences, developed a great group of friends from all cancer realms, and I've received invitations to attend other cancer events and give presentations to groups of professional clinical researchers.

Never underestimate your role as an advocate. Your voice on behalf of others who don't have the ability to or can't speak out is invaluable!

For patients who are possibly considering advocate roles and want the opportunity to be heard, work with organizations like Fight CRC who will help place you in comfortable settings to help you grow your voice. I encourage you to attend conferences and ask questions in the Q&A sessions, ask for emails and contact information, and follow up by reaching out to conference organizers because they really want to involve advocates!

It's imperative for patients to be involved in research because without the patient's perspective, researchers may not understand that *quality* of life is even more important than *quantity* of life for most survivors. We want researchers to know that we appreciate all of their efforts in finding new forms of treatment, and the patient's perspective will keep important research funded with new clinical trials on the horizon, bringing new treatments to cancer patients sooner.

## **READY to DIVE IN?**

Fight CRC's Path to a Cure report is our plan for the future.

This plan is not just for Fight CRC, but for everyone who is willing to champion this cause. Together, with our community of patients, families, and caregivers, we work relentlessly to bring attention to colorectal cancer and all the issues surrounding it. Here's how you can get involved:



Scan to participate in research by finding a clinical trial for you using our **Clinical Trial Finder**.



Scan to learn more about **becoming a research advocate**.



Scan to read Fight CRC's **Path to a Cure** report.



*Do you*  
**HAVE**  
**ENOUGH**  
**TO EAT?**

By **DANIELLE  
RIPLEY-BURGESS**



*It's a serious  
question and one  
that you aren't  
asked enough.*

Food insecurity is a real problem amongst cancer patients, but research shows that patients and their medical teams aren't exactly talking about it—which means patients may not be getting the help they need.

In a 2022 study published in the Journal of the Academy of Nutrition and Dietetics, researchers found that “most registered dietitians believe food insecurity is a serious problem in the United States and has a greater influence on cancer survivors than healthy individuals.”

The study, *Oncology Registered Dietitian Nutritionists' Knowledge, Attitudes, and Practices Related to Food Insecurity among Cancer Survivors: A Qualitative Study*, indicated that many health care teams said **it's rare for survivors and caregivers to notify them they're struggling with having enough food.**

“Oncology patients face a number of barriers and burdens that increase their risks of food insecurity and malnutrition,” Amirah A. Burton-Obanla, MS, told the ASCO Post. She's a graduate student in nutritional sciences at the University of Illinois Urbana-Champaign and the first author of the

study. “They may be sick from the disease and treatment side effects. Many patients experience debilitating fatigue that prevents them from working and hinders their ability to follow dietary recommendations, prepare food, and eat.”

### Caregivers Not Eating

While concerns over getting enough food and nutrition are often pointed toward the patients, caregivers should also be considered. During a podcast at Dana-Farber, senior nutritionist Stacy Kennedy MPH, RD/LDN, CSO, said caregivers need to see their eating like an airplane's oxygen mask—making sure they are getting enough to eat and not simply focusing on the cancer patient.

“Self-care, whether it's through walking, meditation, certainly staying hydrated, making time for them to eat, is important,” she said. “Trying to eat together [with the patient] can be helpful when that's possible, but I think for the caregiver, it's trying to streamline their process—the types of foods that the patient is doing well with, how can they take those same ingredients and have a meal for themselves so that they're not having to do two grocery shops or two different lists or make two different meals. Really try to come together so it helps them to have a little bit more time.”

*Continued on page 28*

## What is food insecurity?

*A lack of access to nutritious foods and a lack of resources to purchase nutritious foods.*

## What should I search for?

Try these terms on Google:



- Meals Assistance **Program near me**
- Cancer Support **Meal Delivery near me**
- Food voucher **for cancer patients**

# FIVE IDEAS for **FINDING** HELP

Unfortunately, there isn't a magic wand when it comes to finding help, BUT, there are several ideas to try if getting enough food is a struggle for you:



Federal programs like **SNAP** are available to those who qualify.



Meal delivery: **Meals on Wheels** is national, and groups like **Mom's Meals** and **N4L Health** can help qualifying patients and those on Medicare and Medicaid.



If you need specialized products and supplements, contact the manufacturer about vouchers, coupons or discounts. Let them know your story; it never hurts to ask!



Local food pantries and nonprofits can provide people with cancer with support, both on a one-time and ongoing basis. **WhyHunger** has a database for community-based organizations and emergency hunger food providers: [networks.whyhunger.org](https://networks.whyhunger.org)



Ask someone local for help: dietitians, nutritionists, social workers, oncology nurses and nurse navigators are all aware of resources. Ask your hospital about any other special programs.

# HOW to HELP OTHERS CHECKLIST

- Coordinate a Meal Train around surgery and treatment days. (Ask about food restrictions!)
- Set up a food delivery service or send gift cards for the grocery store or apps like DoorDash, GrubHub and UberEats.
- Donate/volunteer at your local food shelter.
- Encourage your hospital to set up food vouchers or a pantry for patients.
- Normalize the struggle: If you have a story you'd be willing to share, please tell it.

## Importance of getting enough food

To survive, we must eat. But, it's not always that easy. Access to food can be a major challenge for some patients. Some patients are guided to take nutritional supplements that blow their food budgets. Other patients may not struggle with affording food, but they don't have an appetite or energy to cook, or their diets are extremely restricted. Not to mention misinformation: What should you eat? What should you avoid? It can be very confusing.

## Hopeful Progress

In addition to food's impact on how your body fights cancer, food can also impact your mood. In a study that looked at how a food voucher and pantry program could impact cancer survivors, researchers found the assistance improved patients'

quality of life, and depression scores went down. Additionally, 61% of patients in the study shared the food with other family members, which had to be a good feeling.

There are many reasons colorectal cancer patients and caregivers struggle to eat. But, it's important to keep trying.

If food is a struggle for you, you're not alone. Don't give up, and reach out for help.

## **Do I Qualify?**

Many programs use the poverty guidelines as a basis for qualifications. Scan this QR code to learn more and see if you or a loved one qualifies.



### References

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# FIGHTING DISPARITIES *with* **POLICY**

**Fight Colorectal Cancer (Fight CRC) is committed to health equity, and we are in the fight to reduce health disparities.**

Unfortunately, there are persistent health disparities when it comes to colorectal cancer screening and outcomes in communities of color and rural populations. Fight CRC has been working to address these disparities through our policy work.

As the No. 2 cause of cancer death for men and women, and one of the only preventable cancers, it is unacceptable that colorectal cancer has been neglected for so long. Fight CRC advocates asked Congress to direct the National Cancer Institute (NCI) to prioritize colorectal cancer and develop a strategic action plan. The action plan must address three important issues: the growing number of young people being diagnosed with colorectal cancer; reducing health disparities in screening, care and outcomes;

and developing more effective treatment options. Our advocates were successful, and Congress has tasked the NCI with this assignment.

Another one of Fight CRC's primary policy priorities is the expansion of the CDC's Colorectal Cancer Control Program (CRCCP). The CRCCP was created and designed to reduce health disparities by providing colorectal cancer screening services to underserved populations and high need communities; that includes communities of color, rural communities, and the low income and under/uninsured populations.

The CRCCP currently funds 35 award recipients operating in 32 states. To reach the most vulnerable populations, participants work with clinics, hospitals and other health care systems to implement evidence-based approaches to increase colorectal cancer screening rates among people between 45 and 75 years of age.

Changes that were shown to increase colorectal cancer screening within communities included things like: a reminder system for medical professionals and patients that it is time for screening, providing transportation and child care, extending clinic hours, simplifying paperwork, and offering patient navigators to help patients through the screening process.

Fight CRC and our advocates have asked Congress to increase federal funding for the CRCCP to \$50 million.

More federal dollars means that the program can distribute more awards with the goal of operating in all 50 states and reaching more people. Advocates sent letters to their elected officials and met with Members of Congress in D.C. to educate them on the effectiveness of the program and the benefits of expanding the program, which includes reducing barriers to screening and health disparities.

However, just screening communities is not enough, so Fight CRC is working on a policy that would help patients receive treatment. This new policy would add on to the CRCCP and allow states to provide patients with Medicaid coverage if they are diagnosed through the program. This will ensure that vulnerable populations not only can get screened, but they can receive the necessary care.

For advocates that would like to get involved, the advocacy team can help you connect with your elected officials on these issues. Additionally, every March, our community also has the opportunity to have their voices heard in Washington, D.C., at our annual Call-on Congress event. As always, we will need everyone's support reaching out to members of Congress and sending action alerts throughout 2023.

I hope you'll join us this March and beyond.

ERIN DARBOUZE, MPH  
*is Fight CRC's  
Health Policy Manager*

**FOLLOW ERIN!**

@ErinFightCRC



# WAYS TO Give

Photo Credit: Susie Gaal SPG Photography



"After looking at a lot of different organizations to contribute to, we ultimately decided that Fight CRC was the place we wanted to align ourselves with and support. We feel really confident in the organization because of its track record and because of the passion of the people involved. They care about this at a very deep level. You can tell. They are making an impact at a national level through their advocacy work, and they are bringing together the best and brightest that are focused on finding a cure through the Path to a Cure."

—JEFF INSCO

*Caregiver to his wife Michelle who passed from colorectal cancer, and founder of 317 Foundation*

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 [roxanne@fightcrc.org](mailto:roxanne@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](mailto:michell@fightcrc.org)

## SHOP

[Shop.FightCRC.org](http://Shop.FightCRC.org)

## IN-KIND

To donate products for our events and care packages, contact Katie Newcomb at (703) 647-4693 x814 or [katie@fightcrc.org](mailto:katie@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](http://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](http://FightCRC.org/Donate)





**Tim McDonald**  
STAGE IV SURVIVOR

"Give up drinking, quit smoking, take a walk each day, and get screened."



**Marisa Maddox**  
STAGE III SURVIVOR

"Exercise. I'm not even talking about going to the gym and lifting heavy weights. Simply walking 30 minutes to an hour each day will boost your mind, body, and soul."



**Heather Hardecopf**  
CAREGIVER

"Begin to change out sugar for lower glycemic impact, natural sweeteners. Add plant protein to your diet."



**Cheryl Alston**  
STAGE II SURVIVOR

"Exercise more: Set an intention to move at least 15-30 minutes a day; Self-care: Write your thoughts in a journal and have quiet time to reflect and be in the moment with self; Hydrate first: before coffee or tea, begin the day by drinking a glass of water; and Healthy eating: Always add at least one veggie to your day. Maybe a handful of spinach in your smoothie."



**Marsha Baker**

We asked our community for practical ways anyone can become healthier this March. Here's what a few of our Relentless Champions said:

### **Marsha Baker** CAREGIVER AND HEALTH COACH

Many people began 2023 by making commitments to develop healthier nutrition and fitness habits. March is a great point in the year to assess your goals and achievements so far.

- 1. Begin by making sure your short- and long-term goals are realistic and attainable, and make any necessary adjustments.** Take small steps to achieve sustainable results. Never discount small victories and always acknowledge your successes.
- 2. Use a journal or device to track your daily activities including foods and beverages consumed, exercise and movement, sleep, and mood.** This helps build self-awareness of current habits and supports creating attainable goals to begin developing a healthier lifestyle.
- 3. Remember to check in with your mental health too.** Health and wellness involves taking care of your physical, mental, and spiritual health. Self-care is a necessity for every individual. If you need support, reach out to someone you trust or a health professional.
- 4. Since it's Colorectal Cancer Awareness Month, make sure you're up-to-date with all appropriate cancer screenings and other preventive medical evaluations.** Talk to your doctor and/or schedule appointments, if necessary.



**Alice Marshall**  
STAGE IV SURVIVOR

"Exercise, eat healthy, and get screened at recommended times for all cancers."

# Upcoming Events



## YOU'RE *not* ALONE

### Meet Others Facing Colorectal Cancer

Our Resource Meetups are free online gatherings for people affected by colorectal cancer seeking access to resources and peer-to-peer support.

Whether you have just been diagnosed, are receiving treatment, or are supporting someone who is facing colorectal cancer, these twice monthly meetups are a safe and reliable place to talk to people who have similar experiences to yours while learning about resources available to you from Fight CRC and partners alike.



SCAN

Scan to register for an upcoming meetup.

## JOIN US *in* WASHINGTON, D.C.

This March, we are headed back to Washington, D.C., with a mission: To compel our elected officials to do more to prioritize colorectal cancer through funding for research and screening, and to bring attention to the growing number of young people being diagnosed with colorectal cancer.

You have been Relentless Champions for policy change: We've had so many advocacy wins this past year. It's time to build on that momentum! We must share our stories and urge our elected officials to do MORE to change the statistics and outcomes surrounding colorectal cancer.

### JOIN US IN MARCH 2023 FOR:

- A lobby day (in-person meetings on the Hill will be resuming!).
- The *United in Blue* rally on the National Mall.
- A celebration dinner with some special announcements.

Learn more at [CallonCongress.org](https://CallonCongress.org). If you cannot participate in person, virtual opportunities to advocate will be available! Make sure you're signed up as an advocate to get our Action Alerts.

### CALL *\* ON \** CONGRESS



Scan to get details and register for Call-on Congress.

### CLIMB *\* FOR A \** CURE



Scan to learn learn about the 2023 Climb.

THANK YOU TO OUR  
BEYOND BLUE SPONSORS!



# Time to Flex a #StrongArmSelfie

Support Fight Colorectal Cancer by snapping a #StrongArmSelfie.

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



## Here's How it Works

Take a "selfie" while flexing your best "strong arm" pose. (If someone takes the picture for you, that's OK too.) Then, post it to social media using the hashtag **#StrongArmSelfie** and tag us **@FightCRC** so we can share!



Get more details, learn some tips, and see our 2023 sponsors at [FightCRC.org/StrongArmSelfie](https://FightCRC.org/StrongArmSelfie).



## CONNECT WITH US ON SOCIAL MEDIA and/or IN OUR COMMUNITY OF CHAMPIONS

- [FightCRC.org](https://FightCRC.org)
- [Fight Colorectal Cancer](#)
- [@FightCRC](#)
- [@FightCRC](#)
- [@FightCRC](#)
- Groups**
- [@FightCRC](#)
- [Fight CRC's Climb for a Cure](#)
- [ADVOCATES at Fight Colorectal Cancer](#)



**Fight CRC**  
**Board of Directors**

Back row, left to right: Katie Zahner, Steve Greene, Eric Hausmann, Ron Doornink, Daniel Bloomgarden  
Front row, left to right: Dr. Fola May, Teri Grieger, Dr. Angie Nicholas, Dr. Rich Goldberg

Fight CRC is honored that these leaders are committed to hope and serving colorectal cancer patients!

**Here's who serves on our board, and why they choose to volunteer at Fight CRC in this way.**

**Richard Goldberg, MD**

"Patient advocacy organizations are critical for representing the experiences and desires of the patient and caregiver community to medical care providers, to government representatives, and to the drug and device makers in industry who all provide tools for their care. Fight CRC provides knowledge and support to the patient and caregiver community in ways that complement other available sources. As a medical oncologist who has cared for patients with GI cancer for decades and run clinical trials and two cancer hospitals, I have learned that together we can make a difference. We educate and support patients and caregivers as well as medical providers. We inform policy-

makers and influence legislation and resource allocation. We speak up and persevere in advocating for initiatives that are important to the diverse people and causes that we serve. We have a team of professionals and volunteers who are highly committed to better outcomes and more cures. As a part of the team, I am advocating for, teaching about and learning things that matter."

*Fight CRC is the premiere mission-driven advocacy group in the colorectal cancer arena. We get things done. It is a privilege to be a team member."*

**Fola May, MD**

"As a clinician and colorectal cancer prevention researcher, being a member of the Fight CRC board is so critical because it allows me to use what I have learned about the disease in these settings to help in other important areas like patient advocacy and policy. We still have a long way to go to minimize the impact of this largely preventable disease. The work that Fight CRC is doing is like no other organization when it comes to informing essential policy and research."

**Ron Doornink**

“For me, the fight against colorectal cancer is deeply personal, having lost both my sister and her husband to this disease when they were in their prime, cruelly leaving behind their two young children to grow up without parents. Everything we do at Fight CRC is with one goal in mind: To find better ways to prevent and cure colorectal cancer across every subset of our country’s population because colorectal cancer does not discriminate. Whether you’re from a city or from a small town. No matter your ethnicity, colorectal cancer is an omnipresent issue.”

**Steve Greene**

“As a stage IV colon cancer survivor, I appreciated the support my family and I got from Fight CRC. As a Fight CRC board member, I want to make sure we can expand our reach to help as many families as possible who are impacted by colorectal cancer and ultimately find a cure!”

**Angela Nicholas, MD**

**BOARD CHAIR**

“I am serving on the board as a commitment to the fight that my late husband John took on when he was diagnosed with stage IV colorectal cancer at age 45. About a year and a half into his treatment, he found Fight CRC and he told me that he “found his people.” He became committed to this organization, and recognized there were patients out there who did not have the information he did to fight. He wanted to make sure every person who was diagnosed with colorectal cancer had the same access to information and support like he did. He was so proud to be on the board of Fight CRC because he KNEW he would make a difference and be part of the fight for a cure. When he

died, I knew it was my responsibility to continue in his memory, and to continue his mission to ensure that ‘no one fights alone.’ As a member of the Fight CRC board, I believe that Fight CRC is part of the team helping us get closer and closer every day to curing colorectal cancer. In the meantime, we will continue to offer the support and love for every patient and caregiver that we can reach, like John did each and every day.”

**Eric Hausmann**

**VICE-CHAIR**

“I serve on the board not just to honor my late wife, Rose, but to help us find a cure so we can prevent people from dying from this disease. We have made many strides in the colorectal cancer community. We need to continue doing this on a national level because that is where we can be most impactful. Our Path to a Cure program, our relationship with the CDC, NIH, NCI and the White House, is how we are getting out our message.”

**Teri Griego**

“I serve on the Fight CRC board because I was asked. I have learned what a gift it is to be able to help others. I believe in order to keep something, you have to give it away. Serving on the board is my way of giving hope. As an organization, we fight for those impacted by colorectal cancer by being Champions of Hope—Helping Other People Everyday. It is an honor to serve and a privilege to pay it forward.”

**Daniel Bloomgarden**

“I serve Fight CRC because this is the best organization for what will help drive awareness, advocacy, emotional support for survivors/caregivers, and ultimately find a cure. The amazing staff at Fight CRC is RELENTLESS, and that provides me with so much energy to utilize what I know to help drive our mission. As a stage III survivor, I want to eradicate the threat of colorectal cancer for our children, who are more susceptible to this disease. I am so hopeful because I know this is in our reach!”

**Katherine Zahner**

**TREASURER**

“I eagerly joined Fight CRC to educate, advocate, and assist in finding a cure for colorectal cancer. My passion is driven by my dad’s story. He was diagnosed with stage IV colorectal cancer in 2009 that spread to his liver. He defied the odds by surviving past the five-year mark and is doing well today. I watched my dad fight so incredibly hard and want to dedicate my time to helping find a cure.”



*“We have the best board! I am so honored to work with leaders who are committed to hope and cancer patients. They are exceptional.”*

**ANJEE DAVIS, MPPA**  
*President of Fight CRC*

# FIGHT COLORECTAL CANCER

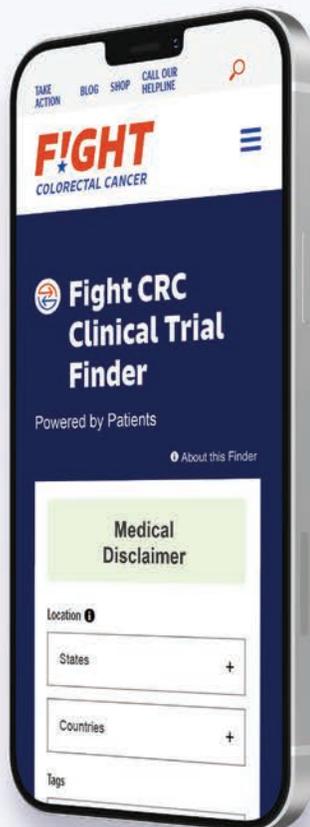
134 Park Central Square, Suite 210  
Springfield, MO 65806

# 47,000+

## Searches for clinical trials and providers .. and counting.

The Trial Finder is a one-stop place to search for and learn about high-impact research studies for colorectal cancer patients.

One click away from the Clinical Trial Finder is the Provider Finder, a digital tool that helps patients find oncologists, radiologists, surgeons and gastroenterologists.



Search for Clinical Trials at  
[TrialFinder.FightCRC.org](https://TrialFinder.FightCRC.org)



Search for Providers at  
[ProviderFinder.FightCRC.org](https://ProviderFinder.FightCRC.org)

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