

BEYOND **BLUE**

FIGHT COLORECTAL CANCER
VOLUME 14 • ISSUE 2



A New Zest *for life*

HOW LIFESTYLE EXPERT
& SURVIVOR BARBARA MAJESKI
Stays Positive

TOP 10 GIFTS
FOR CANCER SURVIVORS & CAREGIVERS

Meet the 2020
Ambassadors

Survivors & Caregivers
**PUTTING A FACE
TO COLORECTAL CANCER**

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

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Volume 14

ISSUE 2

The Power of Positivity



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DISCLAIMER

The information and services provided by Fight Colorectal Cancer are for general informational purposes only and are not intended to be substitutes for professional medical advice, diagnoses, or treatment. If you are ill, or suspect that you are ill, see a doctor immediately. In an emergency, call 911 or go to the nearest emergency room. Fight Colorectal Cancer never recommends or endorses any specific physicians, products, or treatments for any condition.

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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

FIGHT
★
COLORECTAL CANCER





This year, Fight Colorectal Cancer (Fight CRC) wrote a new mission statement:

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.

We intentionally selected each word to guide and direct our future as an organization. We remain focused on the issues that matter to patients, caregivers, survivors, and champions.

Along with a new mission statement, we're also introducing a new look. Bringing in new bold colors, we hope to blaze forward and embrace the spirit that resonates in the words, "relentless champions of hope."

Fight CRC will pour ourselves into the hard work that needs to be done to push for policies that support patients and families. We will bring together the best and brightest in leading research so we see results in increased screening and better treatment outcomes, as well as funding for research.

Beyond Blue is now a resource curated for survivors, by survivors.

Each page is dedicated to providing you with new resources that reflect topics and issues that matter most to survivors and caregivers, with a focus on empowering you and supporting your well-being.

We hope that you'll read, save, and share this information. And—let us know what you think! Tell us your story. Give us your tips. Come to an event. Our community is strong because of our collective voice, and we hope this new-and-improved *Beyond Blue* opens up a way for us to hear your voice even louder. Connect with us on social media or at FightCRC.org!

CONNECT WITH FIGHT CRC

@FightCRC



Your Voice

Best relationship advice for patients and caregivers fighting cancer?

Email your tips to danielle@fightcrc.org for a chance to be featured in our spring issue!



GET BEYOND BLUE FOR FREE!

Beyond Blue is a magazine curated for and by members of the colorectal cancer community. *Beyond Blue* distributors are the force behind this magazine's reach. Each fall and spring, they hand-carry thousands of copies into doctors' offices, hospitals, gyms, health fairs, airports, and more.

To volunteer as a *Beyond Blue* distributor or read this issue online, visit FightCRC.org/BeyondBlue.

Memorial Donations

To honor or remember your loved one in the next issue of *Beyond Blue*, make a financial donation and designate the gift with his or her name. Individuals honored in this issue are listed on page 23. Give.FightCRC.org.



FOLLOW DANIELLE!

@DanielleisB



The Power of Positivity

It only took two seconds after I heard the words "it's cancer" for my mind to enter two fights.

The first fight was obvious—we needed to treat my colon tumor and the cancer in my lymph nodes. But the second fight was not so obvious—it was the silent fight happening in my mind.

"What about my family and future plans? How am I going to live without all of my colon? Will anyone find me attractive? Will I still be able to have a life? What if I don't survive?"

Fear and anxiety brought rapid thoughts that appeared just as fast, if not faster, than my treatment plans. It became difficult to think clearly and regulate my emotions. Throughout my 18 years of survivorship, I've learned I'm not the only one to face this experience. Regardless of if you're under the warm blankets in the hospital bed, or standing at its side, you know cancer is more than a physical fight. It's emotional, mental, and spiritual too.

I don't know about you, but "stay positive" is something I've been told a lot. But how? Why? And what if that's not possible? That's what this issue of *Beyond Blue* seeks to unfold. Medical experts, survivors, and caregivers have all chimed in. What does it take to be a relentless champion of hope? (And, what should we do if we're not feeling it?) I hope you'll dive in and explore the power of positivity with me, and then reach out to offer your feedback and story.

It's an honor to serve you as a fellow colorectal cancer survivor and curate this magazine for all of us in this fight. I hope you enjoy the new-and-improved Beyond Blue!

Stay strong,

Danielle Ripley-Burgess

EDITOR & TWO-TIME SURVIVOR

ABOUT THE EDITOR

Danielle Ripley-Burgess was diagnosed with stage III colorectal cancer at age 17, and stage I colorectal cancer at age 25. She has Lynch syndrome. She's an award-winning communications professional, author, and blogger. Contact her at danielle@fightcrc.org.

NO NITRATES ADDED*



PRO TIP:

When you see a “No nitrates added” label, look for an asterisk pointing to fine print.

When shopping for processed meats, many health-conscious consumers look for products labeled as “no nitrates added” or “uncured.” But we may have been misled, experts say.

A new report finds that deli meats labeled as “uncured” or “no nitrates added” actually contain similar levels of nitrates as those found in meats that don’t carry these labels. A study published earlier this year estimates that about 40 percent of colorectal cancer cases in the U.S. are linked to diet-related factors, including excessive consumption of red and processed meats. So, here’s a consumer tip: When you see a “No nitrates added” label, look for an asterisk pointing to fine print that may say something like “no nitrates except those naturally occurring in celery powder.” That asterisk basically contradicts the nitrate-free claim. If you don’t see an asterisk, the product might indeed be

nitrate-free. “But if you are looking to avoid these chemicals because [you] want to eat healthier, your best bet is to skip processed meat altogether,” Sarah Sorscher of the Center for Science in the Public Interest says. Healthier options, she says, include unprocessed chicken, fish, and, of course, veggies.”

Source: Duped In The Deli Aisle? 'No Nitrates Added' Labels Are Often Misleading Allison Aubrey - <https://www.npr.org/sections/thesalt/2019/08/29/755115208/duped-in-the-deli-aisle-no-nitrates-added-labels-are-often-misleading>

SKIP PROCESSED MEATS

ALTOGETHER



Ambassadors Jennifer Ganser, Lauren Tatum, and Brendan Davis are impacted by young-adult colorectal cancer. Meet all of our 2020 Ambassadors on page 18.

Fight CRC published in *Gastroenterology*

Our work in young-adult colorectal cancer research was featured

Fight CRC published a manuscript in the August 2019 edition of *Gastroenterology* titled, "A summary of the Fight Colorectal Cancer working meeting: exploring risk factors and etiology of sporadic early-age onset colorectal cancer."

Members of the Fight CRC early-age onset colorectal cancer (EAO CRC) working group are now leading the research to better understand the causes of EAO CRC, as well as the best way to approach screening and prevention. Currently, one in 10 patients are diagnosed under age 50. Fight CRC is investing in research and publishing manuscripts to uncover what's behind the phenomenon and how to stop it.



2020 RESEARCH CONFERENCES

Fight CRC is gearing up for the 2020 conferences!

Make sure to sign up to be notified when we host the next GI-ASCO Webinar in January 2020 and send out breaking research news.

FightCRC.org/SignUp



Update to Treatment Guidelines

In March 2019, the National Comprehensive Cancer Network (NCCN) updated their treatment guidelines to include a triplet combination for patients with BRAF V600e-mutated colorectal cancer who have exhausted one to two lines of therapy.

The triplet combination includes:

- BRAF inhibitor *encorafenib*
- MEK inhibitor *binimetinib*
- EGFR inhibition using *cetuximab* or *panitumumab*

Learn about biomarkers at FightCRC.org/Biomarked

emotional triggers

When we have been touched by cancer—as patients, survivors, and loved ones, we can face several traumatic events. The initial diagnosis, surgery, side effects, rounds of chemotherapy, radiation, and more, can make us feel many emotions. Once cancer treatment is over, there are often physical and emotional scars. It is normal to experience events, even after cancer treatments have ended, that remind us of situations pertaining to the cancer experience.

The situations can evoke the same physical sensations, emotions, or thoughts serving as a “trigger,” and reveal emotional scars that could be traumatic stress. Some patients say triggers make them feel like they’re re-living the cancer experience all over again, which could be a flashback, although the events may have taken place in the past.

Managing Triggers

There are many ways to identify your emotional triggers and manage them. You don’t have to suffer! As you get close to an anniversary, like the date you were diagnosed with cancer, talk to someone about that experience.

If you’re faced with something that reminds you of your cancer treatment (like the freeway exit sign), recognize the connection, confront your feelings about it, and bring it up in a support group.

At first, it may seem easy to internalize negative emotions and avoid them. But, this can lead to prolonged stress. While

FACING FEAR OF RECURRENCE

One of the most common emotions that can be triggered amongst people who’ve faced cancer is fear of recurrence.

This can occur with:

- Upcoming scans and tests
- Anniversaries (for example, the anniversary of your first chemo infusion)
- A cancer diagnosis of someone you know
- Death of a family member
- Taste of a meal you often ate during treatment
- Seeing the exit sign you took to get to radiation appointments
- Smell of antibacterial soap used at the hospital

These triggers can easily send both patients and loved ones into tailspins of anxiety. But there are ways to manage.

it might be hard at first, talking about them with others who can relate, or who are trained professionals, can relieve the stress and help you feel supported.

Activities like practicing gratitude (see page 17!), starting a new tradition, and



finding reasons to celebrate large and small successes are just a few ways to take the power back and build up a library of positive experiences after cancer. This can help you overcome negative feelings and find the positive aspects of living with cancer.

Emotional triggers are a common part of the cancer experience. They can help reveal our emotional scars, and just like physical scars, emotions can heal.



PRO TIP:

“When we are triggered, our brains send out alarm bells, even if there isn’t an obvious threat in front of us. It doesn’t mean we are crazy; it means we need to help our body feel safe again.”

–Schuyler Cunningham, MSW, LICSW, LCSW-C, BCD, OSW-C Director, Cancer Trauma Project



WHAT ABOUT PTSD?

According to research, post-traumatic stress disorder (PTSD) affects one in five patients within six months of diagnosis. Often, symptoms improve as time goes on; however, for some people, the symptoms remain or worsen over time.

Talking to a mental health professional or joining a support group are ways to prevent and manage symptoms related to PTSD, stress, and anxiety. It is important to recognize the signs and symptoms, and to get help when needed.

SOME SYMPTOMS INCLUDE:

- Avoiding follow-up doctor appointments
- Experiencing nightmares
- Startling easily
- Difficulty concentrating
- Difficulty sleeping

FOLLOW SHARYN!

@SharynFCRC



Written By

SHARYN WORRALL, MPH

SENIOR MANAGER OF EDUCATION & RESEARCH, FIGHT CRC





NEW ZEST *for* LIFE

Written By
DANIELLE RIPLEY-BURGESS

“

I had never seen another woman go through colon cancer, I didn't have the language or confidence to really say to my doctors, 'I think this could be serious.'

How lifestyle and entertainment expert Barbara Majeski stays positive after fighting stage III colon cancer.

“Look at you sitting there so beautifully, a picture of health!” Kathie Lee Gifford exclaimed after watching the emotional segment about lifestyle and entertainment expert Barbara Majeski fighting cancer to stay alive for her three kids.

The camera panned and cut to a wide image of Hoda Kotb sitting next to Gifford in the studio, across from Majeski and gastroenterologist Dr. Anish Sheth from Penn Medicine at Princeton Health, on a set of identical white couches with a colorful flower arrangement and coffee table between them.

Majeski smiled wide, grateful to be invited into the studio again. But she hadn't traveled to 30

Rock that day for her typical on-air segments about party planning, budgeting, and gift-giving tips. She'd arrived with a different mission: to put a new face to colorectal cancer.

“I had never seen another woman go through colon cancer, I didn't have the language or confidence to really say to my doctors, 'I think this could be serious,’” Majeski said. “I didn't have access to words like colonoscopy. As women, we hear about mammograms and pap smears, about melanoma, but for young women like myself who were healthy, colon cancer wasn't even on my radar.”

Once Kotb and Gifford offered their congratulations, the short

on-air discussion with Dr. Sheth dove into the rising incidence of young-adult colorectal cases, such as Majeski's case. She was diagnosed at age 42. Just before the close of the segment, Majeski offered her final thoughts.

“I'm feeling a whole new lease on life, and I'm grateful.”

And she meant it. Once the studio's ON-AIR lights went off and she returned to her New Jersey home, she lived the next day, and the one after that, differently. With a new mission in life fueled by the desire to help others, she couldn't not live as though she'd been given a second chance.

5



OF BARBARA'S POSITIVE THOUGHTS

True emancipation from suffering is to help others.

—

I don't want other people to go through this.

—

Do right by others and leave a legacy.

—

Feed your mind and the rest will follow.

—

Life is defined by how you deal with your circumstances.

BARBARA'S TIP

How to face a bad day?

I'd recommend a good pair of walking shoes, headphones, and a podcast that's all about positivity.

“

Barbara's podcast recommendations:

Rise
by Rachel Hollis
Revealing Healing
by Ryan West
SuperSoul Conversations
by Oprah
Any podcast featuring
Brené Brown
or Elizabeth Gilbert

have happened. I went and told my doctor about my family history. Those words and that language got me a script for a colonoscopy.”

With a “cancer card” to play, as Majeski explained, the medical teams finally took her seriously. After five years, the cause of her uncomfortable “IBS-like” symptoms was discovered: stage III colon cancer.

Two Chairs

A rush of activity soon followed Majeski as her treatment plans locked into place. She needed over a foot of her colon removed (a colon resection) followed by chemotherapy. Side effects like debilitating neuropathy, a metallic taste in her mouth, and severe struggles with chemo brain brought an onslaught of challenges. Yet chemo wasn't the only therapy she began.

“The timing was terrible, my marriage broke three months before my diagnosis. I was scrambling to make sense of it. I was unglued, devastated, and heartbroken beyond measure.”

But, she felt like she didn't have a choice. “I had to deal with cancer and my marriage. I went from chemotherapy to marriage therapy. I had to do the work to see if the relationship was repairable. Turns out, it was not.”

A cancer diagnosis would have been enough to handle, but Majeski quickly accepted, “The universe doesn't work like that, there are still things that go wrong in life. They're just magnified with cancer.”

Despite her extreme trials, Majeski kept going and vowed to find grace and search for meaning behind the experience for one reason, actually, three.

The Family Secret

There was really no reason for anything to be seriously wrong, or so Majeski thought.

She'd just finished running her second New York City Marathon and was an advocate for good health, a green juice-drinking triathlete who followed all of the rules when it came to diet and exercise.

But, her stomach was chronically bloated, like a “potbelly pig.” She'd experienced stomach pains when putting her kids to bed, and felt constantly lethargic. Concerned, she called the doctor, yet she was ignored and then misdiagnosed.

“I removed dairy and wheat from my diet; I started pureeing foods, she said.” Yet none of her adaptations and doctor's recommendations helped. Symptoms continued to be brushed off by physicians until one fateful day during a baseball game changed everything.

She overheard her dad talking with a gastroenterologist about a tumor he'd once had removed.

“I told him, ‘I didn't know that!’ and he said, ‘Oh it was stage 0 so it wasn't really cancer.’ He had never used the words ‘cancer’ and ‘tumor,’ but instead he'd said, ‘They found a mass and removed it.’ Had I not been sitting there and listening, I don't know what would

“My kids were ages 4, 10, and 12 when I was diagnosed,” she said. “I knew they were watching and I knew attitude is everything. I wanted them to see how to handle adversity. It held me to a higher standard.”

Majeski accepted that life is short—something cancer forces a survivor to see. She vowed to help others were she to be given a second chance and continue living.

“I made a vow to the universe that if I got through this, I would use my voice and gifts to serve others, and live a great life, a life of service. I came to a certain clarity that I’m not done yet, I have more to do. My question became how can I be of service to humanity?”

And in the course of time, it was as though the universe spoke back. She recovered from surgery and finished treatment. Now, as a survivor with “no evidence of disease,” she’s looking for ways to help others survive. Her goal? National television.

Starting Over

“I love television. I grew up watching the Today Show, but didn’t have the courage to go for it. But, after I got through treatments, I knew I wanted to be in media and realized nothing is permanent. So I abandoned fear and went for it.”

Today, Majeski is parlaying her love of entertaining and bringing people together into a career. She signed up for media training and has since received multiple invitations for on-air appearances. In addition to the *Today*



Barbara shared her story with the *Today Show* in April 2019 and is a favorite on-air guest.

Show, she’s appeared on *Inside Edition*, *NY Live*, *The Jam*, and other networks. She hopes to continue in media and plans to release a podcast called “*Baring It All*” in the near future.

“I think being a survivor is a badge of honor,” she said. “I have no shame, secrecy, or privacy about it. I will talk about my cancer and share my story and symptoms with the intention of service. How can I create awareness and use my experience to help others?”

How and why is Majeski so bold and brave? She knows lives are on the line.

“I want to spare other kids the gravity of watching a parent face cancer, or losing a parent to cancer. It’s a responsibility that I feel.”

It’s a responsibility carrying a message that’s catching on amongst friends, family members, and those watching her television segments, like Denise

Taylor on Instagram who posted a comment immediately after seeing her on the *Today Show*:

“Thank you for sharing your journey and the importance of having a colonoscopy. You have motivated me to call for my first one! Shame on me at 52, and I don’t even have a family physician. Thank you!”

It’s comments like these, along with the hundreds of others that pour in, that fuel her life of service and bring a “new zest” into Majeski’s life.

“It’s about resilience...life will hand each of us a card we didn’t anticipate, but we’ve got to get through it. The comeback is always better than the setback.” !

FOLLOW BARBARA!

@barbaramajeski



“

I’m like everyone else. I get into slumps, I can get down, frustrated, and doubtful, especially because my chemo brain never fully recovered. But I don’t want to stay in this space. I’m very quick to say, ‘Enough kicking rocks, Barbara. Let’s rewrite the script and see what we can do.’

JAMIE D. ATEN, PH.D.

Founder & Executive Director of the Humanitarian Disaster Institute

Blanchard Chair of Humanitarian & Disaster Leadership at Wheaton College Graduate School

**STAGE IV SURVIVOR
2020 FIGHT CRC AMBASSADOR**



PRO TIP:

When we can embrace both the positive and negative sides of our feelings, embracing the weight of the negative becomes more bearable.

Q As someone facing cancer, I'm often told to "think positively," but I can't. It's hard to be optimistic. How can I deal with my negative emotions?

A It's common to hear "stay positive" when you face cancer. I believe it's important to think positively, but my personal and professional experiences have taught me that embracing the negative can also be a good thing. There is positivity to be found in negativity. If we don't let ourselves experience struggles, they build up and become more difficult to manage. It's okay to feel negative and have bad moments, bad days, and even bad weeks.

Don't get me wrong; I'm not suggesting you dwell on the negative. Research shows negative thinking is prone to spur on more negative thinking. This can create a difficult spiral where negative thinking leads to negative feelings and negative behaviors that tend to reinforce the latter. But, it's important to remember that it's okay to feel down.

It's okay to feel negative. It's okay to feel sad. It's okay to feel like nothing in life makes sense anymore.

But, instead of focusing on the negative feelings, try and accept the negative and give yourself permission to grieve the pain.

3 Three tips to staying positive

As you handle and accept negative feelings, it will allow the positive feelings to break in. Here are a few practical tips on how that happens:

1 DO SOMETHING THAT MAKES YOU HAPPY

There's no getting around it—cancer is scary. Even though I've been "no evidence of disease" for five years, triggers still pull up unwanted emotional hurts, pains, and fears that make remaining positive difficult, even as a "hardwired optimist," as my friends call me. When this occurs, I try to think about something positive to take my mind off of the negative thoughts. This can include listening to my favorite jazz album and focusing on each note that is played. Other times, it means looking at pictures of my family and friends and recalling the positive feelings I experienced in those moments.

2 DO SOMETHING YOU'RE GOOD AT...NO MATTER HOW SMALL

Sometimes this is enough to break patterns of negative thinking. It can help you get back on track to thinking positively. When struggling with negative thinking, the goal isn't accomplishing something. The goal is simply trying and doing something. Making attempts can bring similar benefits to actually achieving goals, even if you don't accomplish as much as you hope.

Years ago, a client of mine struggled with depression. For a period of time, the biggest goal he could hope for was to make the bed each day. When he didn't feel like getting out of bed, he could at least pull up the sheets

and toss the pillows next to the headboard. This may have seemed small, but it was actually huge. It gave him momentum, which over time built up, and ultimately led him to find the strength to seek counseling.

3 REPEAT STEPS 1 AND 2, AND BE PATIENT WITH YOURSELF

If doing something small didn't help, give yourself time and try again. It might take numerous attempts and repetition for things to work. Maybe you couldn't muster up enough energy to go for a walk. Rather than coming down hard on yourself, show yourself compassion and try something else like talking with a friend. If a conversation feels too daunting, send a short text.

If you feel like you are in a slump or deep sadness for several weeks, it's time to talk to a healthcare or mental health professional.

Through my work as a disaster researcher, I've seen how positivity fosters resilience. As a psychologist, I have seen the power of positivity amidst adversity. Personally, positivity has helped me navigate surviving Hurricane Katrina, as well as stage IV colorectal cancer. It's helping me now through cancer survivorship.

It's important to acknowledge your whole story—the good, beautiful, and joyful—but also the negative, bad, messy, and ugly.

Looking Forward



We caught up with Angela Nicholas, M.D., a caregiver, Fight CRC board member, and wife to late Fight CRC board member and advocate, John MacLeod.

Here are her tips and practical advice for those considering clinical trials from a uniquely personal and professional perspective.

Why should patients consider a clinical trial?

When standard of care treatments stop working, many patients look for other options. There are exciting new treatments that theoretically will work to fight colorectal cancer. A clinical trial is a way for our scientists to take a theory (e.g., this medication might stop cancer because it stops the process that's allowing cells to grow) and test to see if it does stop cancer from growing, or even better, shrink the tumors already in a patient. Many of the current treatment protocols came from clinical trials years ago.

What should people do if they feel overwhelmed when searching for a trial?

The clinical trial process is very overwhelming. Something that worked for me was using the Fight CRC Late-Stage MSS CRC clinical trial finder and filtering it based on location—how far were we willing to travel for the trial and treatment protocols? I would then narrow the trials down to five to ten and send them to John's oncologist. Ultimately, you want to be in a trial that has good science behind it.

What are common thoughts and feelings you experience when trial searching?

I always felt anxious when I was looking for a trial, like my husband's life was in my hands and if I did not find the right trial, it would be my fault. The process does not move quickly. Every location wants a new packet of records, the latest CT scans, an evaluation, and then a decision—and that all comes after someone answers the multiple emails you've sent! It's very tedious and time-consuming, and I can be impatient.

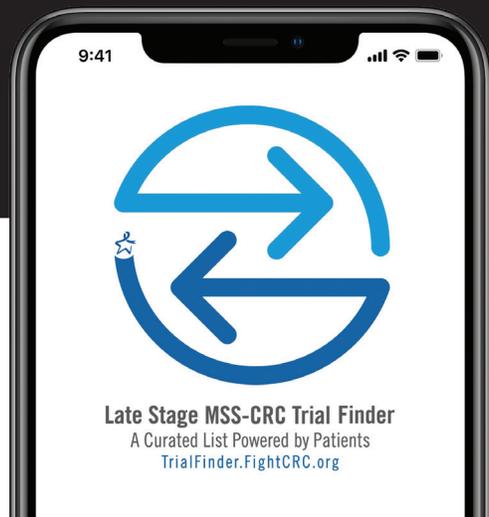
Any advice for people trying to stay optimistic?

The process is tough, however, it helped both John and me to know we were contributing to a cure. Maybe not right now, but for every patient who is in a trial, we learn a little more about the science. This will lead to a cure someday—we kept reminding ourselves of that.

—
Looking for clinical trial resources?

Download our Clinical Trials Mini Magazine at FightCRC.org/Resources and use our Clinical Trial Finder at TrialFinder.FightCRC.org or download the app.

Download the Fight CRC Clinical Trial Finder app today!



A

SPARK

That

A colorectal cancer diagnosis impacts the entire family.

The way it affects caregivers can be a spark that changes the world.

It was the late 1990s and the Internet had begun to connect people in unprecedented ways, including colorectal cancer patients and their families.

Hordes of people facing cancer started logging online and searching for information, advice, and hope. Many with colon and rectal cancers found their way to a Listserv called the Association of Cancer Online Resources (ACOR), which hosted calls each week.

A Glimpse of
15 YEARS
at Fight CRC



2005

Fight CRC established on March 14, 2005

2006

Call-on Congress begins (initially called Congressional Butt-In)

2008

First research grant awarded for \$30,000

2009

MAJOR POLICY VICTORY!
Colorectal cancer funding included in the Department of Defense (DoD) Peer Reviewed Cancer Research Program (PRCRP)

“I DIDN’T KNOW WHAT ADVOCACY MEANT,
 but I wanted to know about research. As a teacher,
 I knew education. Nobody was talking about rectal
 cancer, but when I met Nancy and she said it was
 going to be a ‘colorectal’ organization, I was in.”
 –Pam Seijo, stage IV survivor

CHANGED EVERYTHING

“It was kind of like a current-day conference call where you could join in and listen if you wanted to,” said Pam Seijo, a metastatic rectal cancer survivor. “Once a week, they hosted a chat. I learned I wasn’t alone—there are others out there who have the disease.”

As the Listserv audience grew, so did the awareness of how little support colorectal cancer patients received, and how alone they felt. So in 1999, several of ACOR’s leaders and participants started the Colon Cancer Alliance (CCA). Nancy Roach, a caregiver from Oregon who co-led the ACOR Listserv after her mother-in-law’s diagnosis and helped found the CCA, spent a summer in Washington, D.C. learning how policy and research work together.

“I met amazing people at the Food & Drug Administration (FDA), National Cancer Institute (NCI), and other groups who showed me what could be done through policy and government action,” said Roach.

“I got involved with regulatory advocacy, which was fascinating. They invited me to their training and asked for my input. I learned there are so many squeaky wheels in politics, if you don’t have a squeaky wheel there all of the time, nothing will change.”

Roach had a clear vision, a pathway to a cure! But, there was one problem. Few decision-makers were interested in colorectal cancer, and there were even fewer squeaky wheels. After asking to see the plan for colorectal cancer research and watching a finger point to an untouched binder on a dusty shelf, she was appalled and fired up to do more. Fortunately, she had experience and a group of advocates supporting her.

“While some people were becoming passionate about prevention, marketing, and screening, I started to fade away as an adult child of a patient,” said Judi Sohn, one of the CCA’s founders who lost her father to colon cancer. “I wanted to focus more on advocacy. I had seen it make a significant impact on the special needs community.”

In the summer of 2004, Roach reached out to Sohn, a technology-driven “jack of all trades” and asked for her help.

She also recruited survivors like Seijo and the late Kate Murphy who were eager to support an organization focused on research, advocacy, and education.

“I didn’t know what advocacy meant, but I wanted to know about research. As a teacher, I knew education,” said Seijo. “Nobody was talking about rectal cancer, but when I met Nancy and she said it was going to be a ‘colorectal’ organization, I was in.”

Roach, Sohn, Murphy, and Seijo were joined by a dozen others who formally established the Colorectal Cancer Coalition, Inc. (nicknamed C3 and later renamed Fight Colorectal Cancer) in March 2005. Roach led the vision for research and advocacy programs as Sohn administratively set up the operations as its first full-time employee. Even after its first few months, advocates hit the Hill for lobby days. In 2006, Carlea Bauman was hired as the first president and served for eight years before current president Anjee Davis took over in 2014. Sohn eventually transitioned out of staff in 2011 but stayed engaged as an advocate and volunteer.

2011

Rebranded to become Fight Colorectal Cancer

2013

One Million Strong awareness campaign kicked off on March 1 in Times Square

2014

Fight CRC advocates invited to tour the White House

Your Guide in the Fight released

2015

#StrongArmSelfie social media campaign introduced

2017

Late-Stage MSS-CRC Trial Finder launched



Call-on Congress began with under 30 people and has grown into an event hosting more than 150 advocates each year. Join us in 2020, see page 22!

After my first meeting with my senator, I realized my voice does matter.

I get teary-eyed when I look at where we started and how far we've come.

**PAM SEIJO
STAGE IV SURVIVOR**

the vision is still going strong 15 years later. These three women have stayed positive and serve as a spark, not to mention a major inspiration, for other relentless champions of hope who are joining Fight CRC today. **!**

Judi Sohn (right) and her mom (left) have advocated in memory of her father since the early days of Fight CRC.

“Getting involved in advocacy was the only way I could picture being in a world without my dad,” said Sohn.

“As an only child, we were very close, and this kept him front and center.” As Sohn carried her father’s legacy into advocacy, she inspired thousands of other loved ones to get involved in the cause. What would he think if he saw her today and the impact of Fight CRC?

“He loved technology, and the fact that I’ve made a career of it, where colorectal cancer advocacy was part of it, I think he would be really tickled.”

And while Sohn must speculate about what her father would say, Roach’s mother-in-law was able to witness the organization’s impact firsthand before passing away in 2019.

Seijo and many other survivors are also honored to have the nation’s largest colorectal cancer advocacy community carrying their stories.

From the thousands of meetings spent advocating with policymakers, to the millions of dollars and hours invested into research,

2017

Paper published in *Cancer* following immunotherapy experts meeting; \$200,000 research grant awarded

2018

Screening age lowered to age 45 by the American Cancer Society; Fight CRC supported modeling studies with Dr. Ann Zauber that led to this decision

2019

Paper published in *Gastroenterology* following early-age onset experts meeting

Updated mission statement and brand

**BECOME A RELENTLESS
CHAMPION OF HOPE.**

Join the fight at FightCRC.org



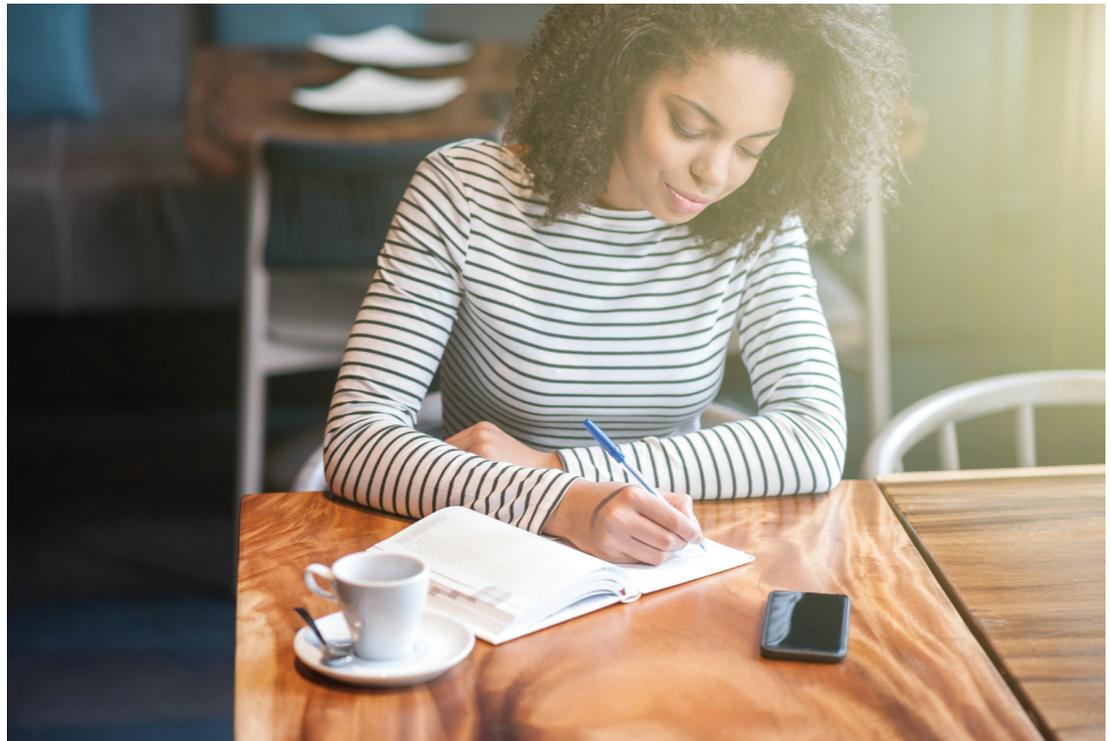
COMPASSION FATIGUE

Compassion fatigue often affects people who are repeatedly exposed to loss, pain, and suffering.

If you or a loved one has been touched by colorectal cancer, you may be familiar with compassion fatigue. Watch an important webinar where Teresa Deshields, Ph.D. explains how to identify compassion fatigue and manage it.



FIGHTCRC.ORG/WEBINAR



New **30-Day Gratitude Challenge**

Did you know that practicing gratitude is a great way to exercise self-care?

It affects emotional, physical, spiritual, relational, and career/educational health! There is no “wrong way” to practice gratitude, it doesn’t cost a thing, and the more of it, the better! Head over to FightCRC.org/Gratitude to download a FREE journal for our 30-day Gratitude Challenge, or order a copy from our store at Shop.FightCRC.org.



PRO TIP:

Download a free journal at FightCRC.org/Gratitude.



Holiday Stress

As we ease into the holiday season, stress goes up, social engagements multiply, diets change, and money gets spent.

Listen to the Fight CRC Taboo-ty Podcast for tips on how to manage some of the challenges that often accompany this celebratory time of the year.



FIGHTCRC.ORG/TABOOTY



TREATMENT SIDE EFFECTS MAGAZINE

Side effects can appear during or after treatment, or years later.

They can cause challenges to daily living activities and they can reduce your quality of life. This resource will help you identify common physical side effects that CRC survivors face. It contains useful tips for managing side effects from patients, survivors, and medical professionals.

Download this resource and more at FightCRC.org/Resources.

2020 **★** AMBASSADORS



Jamie Aten

"I'm in the fight because others fought for me."

STAGE IV SURVIVOR

Wheaton, Ill.

ENTERED THE FIGHT:

July 2014, Age 35

drjamieaten drjamieaten



Dawn Blatt

"I am in the fight for myself, for those currently battling cancer, and to get the word out to go for screening colonoscopies."

STAGE III SURVIVOR

Miller Place, N.Y.

ENTERED THE FIGHT:

November 7, 2016, Age 51

dawn_blatt dawnblatt



Traci Bryan

"I fight for my husband Kevin. Although we are fighting this disease, we are blessed by our faith, family, friends, and those who fight with us."

CAREGIVER

Platte City, Mo.

ENTERED THE FIGHT:

Kevin was diagnosed September 15, 2016, Age 59

tracibryan23



Brendan Davis

"I fight to be healthy again and to live a full life."

STAGE IV SURVIVOR

St. Louis, Mo.

ENTERED THE FIGHT:

January 2018, Age 28

chili_dave



Diego Davis-Olegario

"I fight for awareness, cancer prevention, and a cure. I wish I recognized the symptoms earlier."

STAGE III SURVIVOR

Silver Spring, Md.

ENTERED THE FIGHT:

April 2018, Age 33

diegosaurusrex

diegolegario



Gabriel Figueroa

"I joined the fight inspired by, and in honor of, a dear friend I lost. But now, my fight is bigger. It's for my children, wife, and the younger generation facing colorectal cancer, so nobody else goes through it."

STAGE III SURVIVOR

Downingtown, Pa.

ENTERED THE FIGHT:

April 2, 2014, Age 51



Jennifer Ganser

"I continue the fight that my husband, Chris, started. Cancer took his life, but his passion for life never faded. Even though it's so hard without him here, he wouldn't want us to stop. I keep fighting for my son, Christopher, and for all of our colorectal cancer family."

CAREGIVER

Summerfield, N.C.

ENTERED THE FIGHT:

Chris was diagnosed July 2, 2012, Age 34

jennyhg116 jennyhg116



Jeremy Jungling

"I feel a strong responsibility to pass along inspiration, hope, information, and to show that there is life during and after cancer, even if our time here is shorter than we'd hoped."

STAGE II SURVIVOR

Flowood, Miss.

ENTERED THE FIGHT:

August 29, 2012, Age 38

runstrong.ms runstrongms



Each year, Fight CRC selects individuals who become Ambassadors to put a “face” to the disease.



Maja Kotlaja

“I truly believe no one should fight alone. I want my voice to be heard to empower and activate a community to push for better policies, and to support research, education, and awareness.”

CAREGIVER

Springfield, Mo.

ENTERED THE FIGHT:

Maja’s father was diagnosed in July 2018, Age 50
 marijanakotlaja



Michael Mancini

“I’m in the fight to raise awareness about early-onset colorectal cancer and to advocate for more funding for research and the removal of barriers to screening.”

STAGE IV SURVIVOR

Wolcott, Conn.

ENTERED THE FIGHT:

June 13, 2017, Age 42
 mikesfitnessrevolution
 mmancini74



Patrick Moote

“I’m in the fight because cancer is a real pain in the ass. I refuse to let this situation define me, I refuse to let it be negative.”

STAGE III SURVIVOR

Los Angeles, Calif.

ENTERED THE FIGHT:

May 20, 2018, Age 34
 patmoote patmoote

Meet our latest group!

Stay tuned this coming March for more about their stories during Colorectal Cancer Awareness Month!



Johanna Poremba

“I fight to show that cancer does not discriminate by gender, race, or age. My goal is to end this disease in young people by spreading my message. If you are aware of the symptoms, you can stop this disease before it starts!”

STAGE II SURVIVOR

Hampton Bays, N.Y.

ENTERED THE FIGHT:

November 3, 2016, Age 22
 joposbowl



Denelle Suranski

“I want people to know you can beat this disease and live a long, healthy life after cancer. I want to educate survivors on long-term survivorship and palliative care—something many are missing out on.”

STAGE II SURVIVOR

McKeesport, Pa.

ENTERED THE FIGHT:

August 5, 2003, Age 19
 lemons_into_lemonaid
 lemonaidqueen



Lauren Tatum

“I am in this fight for my two beautiful boys, young adults, and the African American community.”

STAGE IV SURVIVOR

Germantown, Md.

ENTERED THE FIGHT:

May 25, 2019, Age 25

Gifts can cheer us up when we're feeling blue



1

GIFTS CAN TURN A negative day into a positive one within seconds. We asked our Ambassadors, "What is the best gift someone ever gave you because of cancer?"

Here's what they said!



"The best gift I ever received as a survivor of colorectal cancer is unconditional love from strangers that became family."

**DENELLE SURANSKI
STAGE II
SURVIVOR**

STREAMING SERVICE SUBSCRIPTION
(HBO, Netflix, Hulu, and Amazon Prime!)

2

HANDWRITTEN NOTES
of Encouragement

3

RADICAL REMISSION
A book by Kelly Turner, Ph.D.

4

GYM MEMBERSHIP
for Two Years!

5

TIME AND ATTENTION
from Friends & Family

6

COFFEE FROM A Favorite Coffee Shop

7

A DAY OFF
to Focus on Self-Care

8

UNCONDITIONAL LOVE
from Those Who Support Me

9

HOPE AMIDST
the Difficult Road Ahead

10

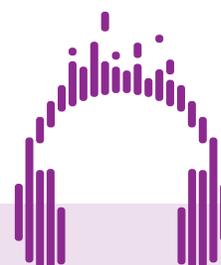
ACCEPTANCE
Under any Circumstances

"I had to do six months of chemo in the form of 6-12 pills per day. My wife got dozens of family and friends to offer motivational quotes, memories, verses, etc. She printed them on small slips of paper and filled my pill box with them each week.

Whenever I took my pills, I had encouraging notes to read.

This helped me immensely and reminded me I wasn't fighting alone."

**JEREMY JUNGLING
STAGE II
SURVIVOR**



BONUS!

We also asked our Ambassadors for song suggestions—what should a "pump up playlist" include? Here are some of their ideas!

Pump-Up Playlist!

- 2 of Amerikaz Most Wanted (Gangster Party) *Tupac* • Lose Yourself *Eminem* • Remember the Name *Fort Minor* • Mama Said Knock You Out *LL Cool J* • Move To The Sound *Afrojack & Laidback Luke feat. Hawkboy* • Eye Of The Tiger *Survivor* • One Swedish House Mafia • We are the Champions *Queen* • Follow Your Arrow *Kacey Musgraves* • Juice *Lizzo* • Formation *Beyonce* • I Will Survive *Gloria Gaynor* • Survivor *Destiny's Child* • Rise Up *Andra Day* • This is Me *Keala Settle* • Ressucita-me *Aline Barros* • Fighter *Christina Aguilera* • Saideira *Santana feat. Samuel Rosa* • Just Be Held *Casting Crowns* • Kick the Dust Up *Luke Bryan* • Callin' Baton Rouge *Garth Brooks* • Paradise by the Dashboard *Light Meat Loaf* • Ali In the Jungle *The Hours* • and several said anything by *Tom Petty and Dave Matthews Band*

Did you know you can dramatically change your outlook by changing your thoughts?

It's something mental health professionals call "cognitive restructuring." Licensed professionals offer Cognitive Behavioral Therapy (CBT) for those who feel stuck, but there are also easy, "at-home" ways to reframe your thoughts. It starts by seeing an example!

Here's how our Ambassadors view some of the most difficult parts of colorectal cancer.

reframing thoughts



Ostomy

"I was proud of my ostomy. I made Instagram posts, and would not hesitate to educate my family and friends about it. It kept me alive. A lot of people have them and live a normal life with them.

The more we bring awareness to something like this, the less scary it becomes."

**DIEGO DAVIS-OLEGARIO
STAGE III SURVIVOR**



Scars

"I used to choke up every time I looked at my scars in the mirror. Now, three years later, I look at them and smile.

They are my battle scars and I am proud of them."

**JOHANNA POREMBA
STAGE II SURVIVOR**

"They are a daily reminder of the opportunity I have and what I'm fighting for."

**GABRIEL FIGUEROA
STAGE III SURVIVOR**

Skin Rash

"Growing up in school, I was teased a lot because I had acne. When the skin side effects appeared, I became apprehensive towards my fiancé and others, and I felt very unhappy. But I eventually accepted the acne-like rash because my doctor advised me that many studies suggest the rash means the treatment is working. I found different facial soaps and creams to use. Now, the rashes do not bother me.

I know I am beautiful and fierce!"

**LAUREN TATUM
STAGE IV SURVIVOR**

Lost a Loved One

"My husband, Chris, passed away from colorectal cancer, but he did not 'lose a battle,' because his fight with cancer continues through me, our son, and the countless others whose lives he has touched. As we share Chris' story, his spirit lives on through us and our fight. We will continue helping others by getting involved and sharing Chris' passion for life.

He never gave up and neither will we."

**JENNIFER GANSER
CAREGIVER**

Get Involved **FIGHT CRC EVENTS**

PRESIDENT

Anjee Davis, MPPA

“At Fight CRC, we say that nobody fights colorectal cancer alone. And we mean it!

We offer many different ways to join our community of survivors and caregivers, from our Facebook groups to in-person events. Fight CRC is here when you are ready to take that next step of sharing your story, finding strength in a community, and turning your pain to purpose.”

FOLLOW ANJEE!

@anjeedavis



CALL * ON * CONGRESS

14th Annual

MARCH 15-17, 2020

Washington, D.C.

CALLONCONGRESS.ORG



CLIMB * FOR A * CURE

AUGUST 17, 2020
Lake Tahoe, California

FIGHTCRC.ORG/CLIMB



**THANK YOU TO OUR
BEYOND BLUE SPONSORS!**



Bristol-Myers Squibb

Genentech
A Member of the Roche Group



MERCK

**NO SHAVE
NOVEMBER**



PiedPharma

HONORING SOMEONE SPECIAL

Memorial DONATIONS

The legacies of the individuals listed below inspire us every day to FIGHT.

Their loved ones have chosen to make a donation to Fight Colorectal Cancer to honor or remember them. A donation is a thoughtful way to recognize someone

affected by colorectal cancer. Donations go to support year-round advocacy efforts, research, and patient education. Thank you for trusting Fight Colorectal Cancer to keep these voices heard.

Those listed below were honored/remembered through donations made from 1/1/2019 through 6/30/2019.

IN HONOR

Alejandro Potes	Gary Robertson	Paula Chambers
Amanda Houston	Grandpa Gross	Peter Caress
Amy Garcia	James Miller	Regina Lynn
Andrea Kramer	Jennifer Ganser	Wooden Fincher
Bhupinder Mangat	Jennifer Noel	Rob Kramer
Bob Ceragno	Hammond	Robbin "Pam" Mann
Bob Leonard	Jerome	Robert Shellemann
Bob Whitehead	Villavecchia	Robyn Shapiro
Brandon Campbell	Jessica Cash	Ronald Smith
Brian Threlkeld	Joey Cutri	Ronnie & Sherrie Ard
Campbell Family	Josh Wimberly	Sean Hallock
Carla Bryan	Karen Miller	Sharon Maxfield
Carole Heaney	Kevin Bryan	Sharon Ostrowski
Craig Campbell	Laura Toth	Shelley Shank
Cynthia Bjork	Lyndsey Pinchick	Steve Greene
Emerson	Maria Heredia	Teresa Van Sloten
Dana Rye	Marisa Maddox	Teri Griege
Debbie Hadfield	Mary Salvi	Terri Brownlee
Diane Kramer	Maureen	Tina Siedler
Dr. Angie Nicholas	McGowan	Trippy Cooper
EL Gran Gibson	Michael Mancini	Trisha Mouzon
Ev Nog	Michelle Cappell	
Evan White	Michelle Insko	
	Mitzi Weissman	

IN MEMORIAL

Adele Burns	Doug Wilson	Kelly Dampousse	Phyllis Dubow
Alice Fay Farmer	Duane Scott	Ken Fetsko	Regina Eubanks
Barnette	Elkie Silver	Kip Brian Hacker	Rhonda Martell
Alice Sell	Emma Gaytán	Kirsten Knudsen	Robert and Dorothy Thornton
Andrew Giles	Gerald Green	Larry Shifflett	Robert Beard
Andrew Wendt	Gerald Wilson	Laura Watkins Toth	Robert Daleiden
Andy Giusti	Grandad Heidrick	Linda Woodard	Robert New
Andy Vezis	Heidi Cardiff	Lisa Dubow	Rose Hausmann
Angela Stacey	Jamie Orth-Taylor	Lori Pogharian	Rosemary Wakolee
April Burns	Jane Zaretsky	Lori Relford	Sandy Connolly
Bernadine Winfrey	Jessica Martin	Luke Perry	Sandy Strobl
Betty Feldman	Houck	Lynn Moxley	Stephen Lindenbaum
Betty OKeefe	Jim Richard	Marco Zovko	Steve Baker
Brett Hagedorn	Jimmy Wages	Mary Ellen Bailey	Steven Plice
Brian Gonda	Joan Bland	Mary S. Wendell	Susan Bernhardt
Bruce Jackson	John Bennett	Melia Richards	Thomas Marsilje
Catherine Holliday	John Bersia	Michael Laursen	Timothy Zalusky
Diggs	John MacLeod	Michael McCracken	Todd Grant
Chris Castellow	John Maple	Molly Dunham	Tom Hasley
Chris Ganser	Joni Haas	Molly Lepor	Ton Jurriens
Clint Cummings	Joseph Johannsen	Neal Hechtkopf	Traci Bryan
Connor Taylor	Josien Doornink	Nelson Gibson	Ty Nguyen
Dave Bushakra	Julia Williams	Nichelle "Nikki" Faulkner	Vivian Fried Allen
David McKenzie	Littlejohn	Olga Yarovenko-Betteridge	Wendy Roehrig
Dawn Rogers	Julianne Gede	Peggy Myrick	William Stout
Palavecino	Edwards		Zenon Szlyk
Debra Kiel	Julie Ann Burn		
Diane Hoplsmazian	Karen Parkison		



Put your loved one's name in the Spring 2020 Beyond Blue issue!

Visit Give.FightCRC.org or call 703-548-1223 to make a donation.



Fight CRC has received high rankings for our streamlined, outstanding financial processes from several groups who watch for proper oversight of donations.

YOUR GUIDE ★ IN THE ★ FIGHT

IF YOU HAVE RECENTLY BEEN DIAGNOSED WITH stage III or IV colorectal cancer (CRC), or have a loved one with the disease, this guide will give you invaluable information about how to understand your diagnosis, realize your treatment options, and plan your path. You have options, and Fight CRC is here to help you navigate the many decisions you'll need to make.



UPDATED
CONTENT!

▶ Get your free copy at FightCRC.org/Guide