

# BEYOND BLUE

**FIGHT COLORECTAL CANCER**

VOLUME 16 • ISSUE 1

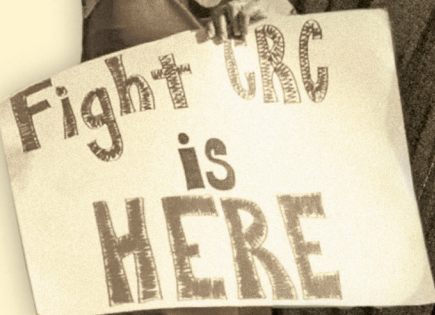
*No Excuses*  
GET INVOLVED IN 2021

*V-I-C-T-O-R-Y*  
WHY ADVOCATE  
VOICES MATTER



*I can't thank you enough  
for your support. Without you,  
I can't imagine I would be here.*

*The* **ORIGINAL  
RELENTLESS  
CHAMPION**  
*of HOPE*



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





# Contents

Volume 16

ISSUE 1

Legacy



## **Editorial Team**

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**05**

## *Message from the President*

Anjee Davis explains how Nancy Roach's legacy inspires us to lead with purpose.

**07**

## *Letter from the Editor*

Two-time survivor Danielle Ripley-Burgess encourages us to plant hope and consider our legacies.

**08**

## *News Feed*

The latest news and updates impacting the Fight CRC family.

**10**

## *Early-Onset Colorectal Cancer: A Global Problem*

Dr. José Perea explains the research being done to understand why many countries are seeing an increase of colorectal cancer in people under age 50.

**11**

## *The Original Relentless Champion of Hope*

Fight CRC Founder Nancy Roach is passing the torch of Board Chair this year. Take a look back at what led her to start Fight CRC and the impact of her legacy so far.

**17**

## *Ask the Expert: Health Equity*

Dr. Fola May explains what health equity means and how all patients play a role in creating equal access to care.

**18**

## *The Squeaky Wheels of Colorectal Cancer*

See where our research advocates are currently serving and why Fight CRC has grown to become a credible, informed voice in scientific circles.

## **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.



**20**

### *Q&A with Rep. Donald Payne, Jr.*

Read how the New Jersey Congressman who stepped into Congress after his father, Rep. Payne, Sr., passed away from colorectal cancer is furthering his father's legacy through public service.

**23**

### *Pulling Back the Curtain on Capitol Hill*

Molly McDonnell explains how progress is made when advocates share their stories with lawmakers, both in person and virtually.

**24**

### *A \$2 Million Legacy*

The Hill family began No-Shave November as a way to remember their father. So far it's raised more than \$2 million for Fight CRC, and it has inspired others.

**25**

### *Patient Resources*

Spotlighting some of Fight CRC's medically approved resources for patients!

**26**

### *Meet the 2021 Ambassadors*

Get to know the relentless survivors and caregivers serving as this year's Fight CRC Ambassadors.

**30**

### *Top 10: What I Wish*

After several years of focus groups, here's what Fight CRC's Patient Education and Research Team learned what advocates wished they had at diagnosis, and what they need now.

**31**

### *Get Involved*

Upcoming events and ways to connect at Fight CRC.

**33**

### *Practically Speaking*

Darah Curran shares ways to face end-of-life care and conversations.

**34**

### *Memorial Donations*

Tribute gifts made in honor and in memory of our relentless champions of hope during 2020.



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)*

**FIGHT**  
★  
COLORECTAL CANCER

Join the Fight at **FIGHTCRC.ORG**



Claudette Judkins >  
Stage III Survivor

# NO EXCUSES.

GET SCREENED FOR COLORECTAL CANCER.

More than 50,000 people die of colon and rectal cancers each year and timely screening could have prevented many of those deaths. Talk to your doctor about when to get screened and encourage your family and friends to get screened, too.

**SCREENING SAVES LIVES.**





## Lead with Purpose

In 2005, Nancy Roach founded Fight Colorectal Cancer.

A cancer survivor, caregiver, and a woman who lived with conviction to help others, Nancy funneled her passion into founding this organization. She was a caregiver helping her mother-in-law navigate a colorectal cancer diagnosis and she couldn't find a community. That was the spark she needed to change the world. Over the last 20 years, Nancy has pushed policy, supported a community of activists, and ultimately, provided hope for so many of us.

True story: I met Nancy for the first time over breakfast in Washington, D.C. It was my first day on the job at Fight CRC, I'd just been hired as the Vice President of

Programs. We had a one-on-one meeting and she looked at me and said, "Can you do this job? Because we need someone who will actually make sh\*t happen." I found myself strangely intimidated. Her vision was, and continues to be, laser focused. Fight CRC exists to make things happen and to improve the lives of patients. Period.

Nancy hasn't changed from that first breakfast. She continues to challenge our team to be creative, be authentic, and ensure we deliver our mission with integrity. Her life values and purposeful commitment is woven into the DNA of Fight CRC. From our board members, to our staff, to the volunteers we work with across the country, we lead with purpose. Nancy has set the example.

Today, our community of champions is full of hope and we believe in a better future for colorectal cancer patients. While a lot has changed and improved since Nancy founded Fight CRC in 2005, we have a lot more work to do. And we're ready. What Nancy began, we plan to continue. This is not only her legacy, but it's ours.

**We will relentlessly pursue a cure until nobody hears the words, "You have colorectal cancer." It's our mission, and it's what Nancy would do.**

**FIGHT CRC PRESIDENT**



### Upcoming Leadership Changes

Read more about Nancy Roach and upcoming leadership changes at Fight CRC on page 11.

### **FOLLOW ANJEE!**

@anjeedavis





# Q • In what ways are you or a loved one leaving or carrying on a legacy?



**STEVE GREENE**  
*Stage IV Survivor & Board Member*

"As a stage IV colon cancer survivor, I think about my legacy often. I ask myself the questions, 'Why did I survive and what is God's plan for me?' The one answer that always comes back to me is to be involved in the colorectal cancer community as an advocate, a volunteer, and as a board member of Fight CRC. I've been inspired by so many wonderful people within this community and I want to be part of the legacy of continuing to help others fight the disease and ultimately find the cure!"



**KRISTINA SMITH**  
*Caregiver*

"My legacy is inspired by one of the last promises I gave to my late husband: To raise our son, Porter, into the man he would want him to be. With that being said, I am intentional on my late husband's birthday and the anniversary of his passing. Porter and I ensure we are doing something special to honor him. We have flown in a helicopter, helped families with needs for a new foster kid, raised funds for an annual scholarship for high school graduates that have lost one of their parents prior to graduation, and we travel the world to see the beauty in all that God has created. We have created beauty from ashes and turned pain into purpose!"



**SHAYE DUNN**  
*Stage III Survivor*

"I've always hoped that when my time on Earth is over, people will remember my ability to find humor in almost every situation, no matter how bad it seems. We often take life too seriously, and once you've been diagnosed with cancer like I was at age 36, you realize you should be more concerned about enjoying life than stressing over things you don't have control over! I wrote a book and poke fun at some of the harrowing things I've encountered because I hope to sprinkle a few giggles into the universe and help current patients and survivors alike have a good laugh. Laughter really is great medicine, and I hope it will forever be associated with my legacy!"



**RACHELLE BABLER**  
*Loved One*

"Sharing my sister's story is part of my healing from losing her and how I carry on her legacy. One way I did this is through writing a song. She was 45 years old when diagnosed with stage IV colon cancer. Her symptoms were initially ignored because of her age and she fought her two-and-a-half year battle with nothing but strength and grace. Throughout her journey, she advocated for others to get screened and shared the importance of it. Colorectal cancer, when caught early, is the most treatable and preventable cancer there is. Don't delay, get screened. It could just save your life."

*Rachelle (pictured left) and her two sisters at Juanita's (pictured middle) chemo kick-off party*



## Spotlighting Dr. Charles R. Rogers

*Cancer Disparities Researcher & Caregiver*

Dr. Rogers' research agenda has contributed to translational solutions that address the complex underpinnings of cancer and men's health disparities, with a primary focus on colorectal cancer awareness and prevention among African-American men, for over 10 years.

Personally, he is a caregiver to his wife, who was diagnosed with early-onset breast cancer in 2020. Every day, he is leaving a legacy for the next generation.

*"2020 taught me that being a cancer caregiver calls you to lean into love in ways that you did not know possible." #TeamThrive*

**TELL US**

**What is the best nutrition advice you've ever received (and stuck with!)?**

Email your story to [danielle@fightcrc.org](mailto:danielle@fightcrc.org) for a chance to be featured in our next issue!

**FOLLOW  
DANIELLE!**

@DanielleisB



#### **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](mailto:danielle@fightcrc.org).

## **Planting Hope**

At the onset of COVID-19, I got really into gardening.

Previously, I had dabbled in growing my own fruits and veggies, but that was nothing compared to what I did at the start of the pandemic. Not only did I begin watching YouTube videos and buying books about gardening, I tried something new. This fall, I planted bulbs.

If you're not familiar with bulbs, they work like this: If you want the colorful tulips, daffodils, and peonies in springtime, you plant dry roots into the ground during fall. The roots don't look moist and vibrant (they look the exact opposite), but the experts claim they work. After sitting under the soil throughout the fall and winter, the bulbs transform and give life to colorful blooms in spring. The practice of planting bulbs is a great metaphor for planning a legacy.

Sometimes, the word legacy can spark sadness, fear, and grief. If you search online for "legacy," you'll find an assortment of funeral homes, churches, and retirement plans. Although many in our culture associate legacy with passing away, the idea of leaving a legacy is much bigger than facing death. Legacy is about life.

Thinking about legacy will drive us to be intentional about how we invest our time, dollars, and energy. It sparks vision. A legacy mindset understands that each day counts, and it helps us be relentless. Choosing to invest in people, projects, and policies that will outlive us can bring hope and peace. It's done this for me.

As a two-time survivor, getting involved at Fight CRC is one way I am leaving a legacy. Sharing my story, advocating for systems change, donating toward the cause ... these are activities that impact others' lives both now *and* in the future.

Throughout this issue of *Beyond Blue*, you'll meet others who are actively planning a legacy. Our newest Ambassadors have gone public with their personal stories, medical providers and researchers have dedicated their careers to help others, Rep. Donald Payne, Jr. just got a bill for colorectal cancer screening passed on the Hill, and advocates are going above and beyond, just like our original advocate and founder Nancy Roach.

Legacy is about the past, present, and future. The idea of it sparks hope. Even if we don't see our impact today, it will come.

**Legacy is a lot like the bulbs I planted a few months ago. I may not see anything but dirt right now, but I'm counting on a beautiful garden this spring.**

Have hope!

*Danielle Ripley-Burgess*

**EDITOR & TWO-TIME SURVIVOR**



# V-I-C-T-O-R-Y

We never gave up and we never backed down. For eight years, Fight CRC champions asked Members of Congress to pass the Removing Barriers to Colorectal Screening Act, nicknamed the “Medicare Loophole” bill, and our hard work paid off. In December 2020, the bill was passed!



## Four New States to Tackle Screening

Our Catalyst State-by-State Advocacy Program recently awarded grants to four states who are focusing on increasing access and reducing barriers to screening.

Fight CRC provides funding and technical assistance to support grassroots activities and coalition-building that will lead to state-level legislative and policy changes to advance screening. Congratulations to advocates in Kentucky, Nebraska, Rhode Island, and Texas!



Check out [fightcrc.org/catalyst](https://fightcrc.org/catalyst) to learn more.



### PROTECTING PATIENTS

#### Free Masks Available

At the start of the pandemic, Fight CRC wanted to support patients in tangible ways. That's why we've given away more than 8,000 free masks. Masks are still available, request yours at [shop.fightcrc.org](https://shop.fightcrc.org).

**\*SHIPPING COST IS \$5**



## Huge Steps Forward

### USPSTF Guidelines

We are still celebrating the U.S. Preventive Services Task Force's plans to lower the recommended screening age to 45 for average-risk individuals! Together with our partners at the Colorectal Cancer Alliance and Colon Cancer Coalition, we rallied the community to send in a flood of support and share our stories. Now, we await the final decision.

*"The USPSTF draft recommendation of lowering the screening age to 45 aligns with the goal of capturing a population of vulnerable patients in whom we can prevent colorectal cancer, or catch it at its earliest stage."*

 @SOPHIEBALZORAMD

## Spreading Out

### Reaching New Communities with Tech

Looking at the nationwide health care provider network and U.S. Census data through our partnership with Komodo Health, we are now getting our resources into the hands of those who need them the most!

*This technology allows us to target communities with colon and rectal cancer patients and get resources like our Spanish translations (and this magazine!) to them.*

## The Counts Are In: Advocates Flexed the Vote

From voter registration, mail-in and absentee voting, and safety at the polls, Fight CRC's Advocacy Team made sure advocates' voices were heard during the 2020 Election!

More than 2,400 advocates pledged to vote, and many of them were first-timers! We will continue to engage our community through action alerts involving policies about screening and research funding. If you're not signed up to take action yet, go to [fightcrc.org/advocate](https://fightcrc.org/advocate).



**MORE THAN**  
**2,400**  
**ADVOCATES PLEDGED TO VOTE**



## Wakanda Forever

### Chadwick's Legacy

The world was shaken when actor Chadwick Boseman passed away from stage III colorectal cancer in August 2020. While fans continue to mourn his unexpected diagnosis and death, many of his supporters have kept his legacy going by making donations to colorectal cancer groups. Fight CRC received several donations in honor of the beloved Black Panther. We promise to apply the funding toward research, advocacy, and education—with a focus on addressing health disparities.

## SPREADING THE WORD (NOT THE VIRUS)

### COVID-19 Survey Results

The results from our COVID-19 survey of the colorectal community continue to inform and educate! In addition to *Reuters* and *The New York Times* covering the report, we have presented the research at the Colorado Cancer Coalition's Annual Symposium and GI ASCO!

Read the report at [fightcrc.org/covid19](https://fightcrc.org/covid19).

## WEIGHING IN

### President's Cancer Report

President Anjee Davis represented the relentless champions of hope as a member of the virtual President's Colorectal Cancer Screening Panel in November 2020.

The Panel monitors the activities of the National Cancer Program and reports to the President of the United States on barriers to progress in reducing the burden of colorectal cancer. Anjee provided input about the opportunities, barriers, and possible solutions to improve colorectal cancer screening during and post COVID-19.



# Early-Onset Colorectal Cancer: A Global Problem

BY DR. JOSÉ PEREA

Did you know cancer research is happening all over the globe?

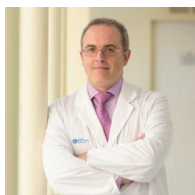
International research relationships are critical when it comes to adequately studying diseases. This includes early-age onset colorectal cancer (EAO CRC), which is also referred to as early-onset colorectal cancer (EOCRC) by some researchers and organizations. By looking beyond our borders, we see how disease affects a more diverse population of patients and we gain more knowledge. For example, incidence of early-age onset colorectal cancer is on the rise in many countries, but not in Italy. Working alongside the international research community will unlock clues to phenomena such as these. These clues can only be found while working together.

Dr. José Perea is a global expert on colorectal cancer and a member of Fight CRC's Early-Age Onset Colorectal Cancer Workgroup. We asked him to share what researchers are finding regarding early-onset cases and the current research being done to understand what's happening.

## The Situation

Early-onset colorectal cancer (EOCRC) defines colorectal cancer cases diagnosed in patients younger than 50 years old. The increasing incidence of EOCRC is undeniable in many countries worldwide. Among these increases, some countries have rates that are striking, such as the USA and Canada. Other countries are seeing rates grow, but not so intensely. There are also some countries where EOCRC is less striking, where the rates remain stable or, in some cases, low. This is the situation in a few European countries.

The proportion of cases that are said to be associated with hereditary cancers is more or less stable, while rates of sporadic EOCRC (not linked to an inherited or genetic predisposition) are what seem to be clearly increasing. This is much more in relation to cases located in the rectum.



## Current Research

Until now, studies have been aimed at differentiating EOCRC from colorectal cancer that appears at later ages, also called late-onset colorectal cancer. These studies have looked at:

**A MOLECULAR POINT OF VIEW:** looking at differential features, possible alternative pathways, or differential genes involved compared with late-onset forms.

**RISK FACTORS:** overweight, type II diabetes mellitus, lack of physical activity, a family history of colorectal cancer, among others.

**IMPORTANT DISPARITIES:** race/ethnicity, sex, or geographic areas, among others.

Today, many of the studies are also focusing on factors like exposure to environmental factors from early ages of life, lifestyle habits, and the microbiome. Given the universal magnitude of the problem, studies focused on EOCRC encompass a large number of cases and try to involve different geographic areas. Our goal is to not only understand how EOCRC is similar to CRC developed later in life, but also how it is different. It is very likely that it is. New computer applications like artificial intelligence and machine learning will undoubtedly help in our aim.

## Importance of the Patient Voice

Efforts to raise awareness about the problem in the general population, as well as to the corresponding authorities, should not be forgotten. Fight CRC plays an important role in educating and informing the population. Fight CRC is also convening an international research community, the Fight CRC EAO CRC Workgroup. We are working together to organize meetings and webinars that bring together experts on the subject from all around the world. This helps us update knowledge of the problem or create new initiatives in terms of studies and collaborations.

EOCRC is a global problem and understanding it will take collaboration from researchers all over the world.

This is one reason Fight CRC and the Fundación Jiménez Díaz University Hospital in Madrid, Spain, are organizing the 3rd EOCRC International Symposium for June 2021, which will be virtual. In addition to round tables and talks by experts, and the presentation of scientific abstracts, we are dedicating a day to hearing from patients and specialists. I hope you all can attend!

Finally, something that must be taken into account when discussing EOCRC, and something that makes up a significant proportion of preventable cases, is that anyone who has cases of colorectal cancer or polyps in the family, especially families with early-age diagnoses, should contact their doctor. In these cases, necessary screening strategies should be carried out, especially if there are digestive symptoms of any kind. It is better to rule out these symptoms and prevent EOCRC than to be too late.



## EOCRC or EAO CRC?

Throughout the scientific literature on colorectal cancer, you'll find the terms early-onset colorectal cancer (EOCRC) and early-age onset colorectal cancer (EAO CRC) used in reference to colon and rectal cancer occurring in patients younger than 50 years old. You may also see the term "young-onset," which is also referring to this scenario.

Dr. José Perea is a Consultant Surgeon of the Surgery Department and Principal Investigator of the Research Institute at the Fundación Jiménez Díaz University Hospital in Madrid, Spain. He is a Board Member of the World Journal of Gastroenterology and a Member of the Board of the Spanish Association of Coloproctology (AECOP) as well as a Member of Fight CRC's Medical Advisory Board, Founding Member of the Colon Cancer Foundation's Integrated Medical Advisory Committee, and he was recently named a Member of the Meeting Planning Committee of The Collaborative Group of the Americas on Inherited Gastrointestinal Cancer.



# The ORIGINAL RELENTLESS CHAMPION of HOPE

Feature STORY

*Fight Colorectal Cancer -  
There is another donation in  
Memory of  
Scott Valianos (1966-2016),  
my son.*

*Thanks for all you do to  
raise awareness and to  
fight for a cure.*

*No one should have to  
suffer the way my son  
did, for five years.  
I will miss him everyday  
forever.*

*Thank you,*

*Jolita Valianos  
Cambridge, MA*

**NANCY ROACH** is **PASSING the TORCH**  
to a new Board Chair after 15 years of leading  
Fight CRC and leaving a legacy that will ripple  
throughout future generations.





BY *Danielle Ripley-Burgess*



**OVER 15 YEARS AGO,** a fire inside of Nancy Roach sparked what would become Fight Colorectal Cancer. Here's the story of how one woman's passion and courage led to THE nation's leading advocacy organization focused on colon and rectal cancers, and the vision that's carrying us into the next decade.

**“We were ticked off because there was nothing for colorectal cancer.”**

It was 1996 and Nancy Roach's mother-in-law had just been diagnosed with stage II rectal cancer. Roach found herself doing what many patients and caregivers still do today—logging online and looking for resources, answers, and hope.

She quickly found a group of smart, committed patients and caregivers who weren't only sharing ideas and tips about treatment, they were pursuing ways to get colorectal cancer into a bigger spotlight. Treatment options were lacking and research funding fell short.

The group's passion eventually spilled over from online gatherings to in-person meetings. Soon, they founded the Colon Cancer Alliance (CCA) in 1999. Tasked with leading advocacy efforts for the CCA, but clueless about what advocacy meant, Roach spent a few weeks in D.C. learning from a lobbyist. He taught her the D.C. landscape and how to boldly enter a congressional office and respectfully apply pressure. The education transformed Roach into a relentless advocate.

“I saw the difference a group can make because if you have people who understand how to put pressure on political, health care, and research systems, you can make a difference for not just one patient, but all patients,” said Roach.

As the CCA began expanding its programs and offering more direct patient support, Roach's heart became set on advocacy. She wanted to make a difference. She began working alongside the Food and Drug Administration (FDA) on compassionate use and expanded access. Because there was no one else talking about policy and research around colorectal cancer, she stayed involved with groups like Once Voice Against Cancer and the National Cancer Institute (NCI), pushing them to make decisions on behalf of colon and rectal cancer patients.

Frequently traveling coast-to-coast from her Seattle-area home to the D.C. area, she soon realized that people touched by colorectal cancer needed an army of voices to promote change. Her one voice needed to be amplified. After securing financial support from three sponsors, she established C3: Colorectal Cancer Coalition on March 14, 2005. This would evolve into the Fight CRC of today.

15  
11  
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16  
154 G  
162  
155  
138  
126 R



## 70,000 CHAMPIONS STRONG

Nancy Roach founded Fight CRC in 2005 with three sponsors and a handful of supporters. Today, we are THE nation's leading advocacy organization with more than 70,000 champions actively engaged in advocacy, research, and/or patient education.

## GAINING INFLUENCE

Staff, board members, and advocates slowly began joining C3, which was renamed Fight Colorectal Cancer in 2011. With Roach serving as Board Chair, both the organization, and her influence, grew. Committed to the initial vision of watching policy and research work together, Roach stayed laser-focused on research advocacy. She laid the framework for the Research Advocacy Training and Support (RATS) program and continued networking throughout D.C. agencies. Anything she could do, she did, like volunteering on countless grant review panels, co-authoring papers, and attending scientific meetings, all to share the patient perspective. A prominent "squeaky wheel" during a 10-year project with the NCI, she supported efforts to transform the clinical trials system in the United States.



"When I started Fight CRC, my goal was to have personalized, curative treatment for every single person diagnosed with colorectal cancer and a \$2 non-invasive, very accurate screening test. The goal of everything we do is to push the system in that direction, but the system's not set up to go in that direction. So, this means we push all the time, constantly," said Roach.

**WE ARE  
NEVER  
BACKING  
DOWN.  
*Ever.***

# TAKING UP *the* TORCH



## Meet Dr. Angie Nicholas, the new Board Chair of Fight CRC.

- Joined the board in 2019, taking the seat of her late husband, John MacLeod
- Serves as Chief Medical Officer at Einstein Medical Center

**RESIDING IN**  
*North Wales, Pennsylvania*



Use your smart phone to scan this code and read more about Dr. Angie!

*Don  
wagner  
of fightcnc*

THINKING OF YOU *all*  
WITH SMILES AND WARMTH...  
AND A WISH FOR HOLIDAY JOY.

*Thanks for all  
you do!  
Here's to a great 2020*

Join the Fight at **FIGHTCRC.ORG**





**ABOVE** Nancy and some of the first research advocates. **LEFT** Nancy and survivor Jovannie Lorenzo flex a #StrongArmSelfie

## FIXING WHAT'S BROKEN

To understand the fire that fueled Roach's advocacy, one needs to know the notorious "binder story." Roach tells it like this:

"I knew that a Progress Review Group for colorectal cancer had met, but I hadn't seen anything come out of it. So, when I was in D.C. in 2004, I made an appointment at the NCI to get updated. I walked into the office and asked, 'Where's the report? What happened to it?' and a man pointed to a binder on his bookshelf and said, 'It's right there.' That pissed me off. I decided right then and there to start Fight CRC because if we had been in place then, the Progress Review Group would have been implemented in a much more robust way."

**Fight CRC was born when she walked out of that meeting. Since then, thousands of patient lives have been improved, lengthened, and saved.**

For 15 years now, advocates like Roach have refused to back down, applying immense pressure to fix broken systems impacting colorectal cancer patients. Fight CRC has supported efforts such as training advocates at Call-on Congress to advocate for funding research and demand equal access to care, awarding millions of dollars in kickstarter research projects, and convening experts in immunotherapy and early-age onset colorectal cancer research.

As a direct result of Fight CRC's pushing, the Department of Defense (DoD) now funds colorectal cancer research, more patients are searching for and enrolling in clinical trials, Congress has passed legislation to fix

insurance loopholes and remove barriers to screening, and dozens of Fight CRC advocates are well-respected and sitting on influential research committees within the scientific community (see page 18).

"When my mother-in-law was diagnosed in 1996, there was only one drug available for treatment, Fluorouracil, or 5-FU. More chemotherapies were approved in the late 90s, and since then, there have been even more. Now, there are over 15 drugs available for people with metastatic colorectal cancer! Patients can cycle through combinations and live a lot longer. Some patients' tumors can be cured, or they can live with long-term, stable disease. There are miracle stories coming out



## "BEING RELENTLESS MEANS PURSUING THE GOAL EVEN IF OTHERS DON'T GET IT."

Some may think your goal is crazy, stupid, or not worth it. But they're not you. They don't want what you want. Such relentless pursuit of a goal makes people uncomfortable because it reveals a lack of passion in their own lives. Get around other people who are in relentless pursuit of their goals and you'll find people who understand, people who are willing to support your efforts."

**—NANCY ROACH**





of research. This is what I always wanted to see. Now the question is how to take what's working and apply it to all patients. This is where we go from here," said Roach.

## TORCH PASSING

All great leaders know sustainability takes change and growth. One flame isn't enough to keep a fire going; others' flames must catch on too. Today, Roach's vision of raising an army of advocates is happening. Thousands of relentless champions of hope are following in her footsteps. We know that being relentless means facing obstacles. It means not giving up when roadblocks appear. It means channeling our personal frustrations over unjust systems into advocacy, just like Roach did, and letting that passion transform into fuel.

Fight CRC is fortunate to have been led by a founder who has never wavered from wanting to change lives by getting personal. However, her own personal life has undergone quite a few changes. Her inspirational mother-in-law passed away in 2019,

but a bundle of joy in fall 2020 helped soothe the pain. As a new grandma, Roach has caught a fresh vision for her life and she is heading in a new direction. This means she is passing the role of Board Chair to someone else and slowing down her advocacy efforts.

"My grandchild gives me a different way of looking at life, knowing I have a new generation moving forward," said Roach. "I want to tell him that you don't have to die if you get colorectal cancer, it can be caught early, and if it's not, there's a cure for you and everyone diagnosed."

Our Fight CRC family will forever be grateful for the 15 years of relentless passion and purposeful leadership from Roach. She has changed the trajectory of the colorectal cancer community. Although we will miss having her flame leading our charge, we're excited to see her experience something few others get to do: watch her legacy unfold.



**FIGHT  
COLORECTAL  
CANCER!**

THANK YOU FOR ALL  
THE ~~WARRIOR~~ HARDWORK  
YOU'VE BEEN DOING TO FIGHT  
SUCH A DEADLY DISEASE!  
IT IS ORGANIZATIONS LIKE YOURS  
THAT MAKES THIS WORLD SUCH  
A BEAUTIFUL PLACE.  
CONTINUE TO CHANGE THE  
WORLD FOR THE BETTER!  
YOU ARE ALL RELENTLESS  
CHAMPIONS!

Peace & Love  
*J. Bell*  
JORDAN CUELLAR

**ABOVE** Nancy and Candace Henley, Founder of the Blue Hat Foundation, share a moment during Call-on Congress.



# Has Colorectal Cancer Impacted Your Life?

Every day, millions impacted by colorectal cancer search online looking for stories of people who've also faced this disease. When you share your experience, you let others know they are not alone. And you can connect with other champions of hope, too.

Share your story with us at [fightcrc.org/shareyourstory](https://fightcrc.org/shareyourstory).

< Michael Mancini  
Stage IV Survivor







**DR. FOLA P. MAY**



**I've heard about “health equity” but I'm not sure what it means. What is health equity, and how can I get involved and/or help as a patient or caregiver?**

**A:** Health equity means that all people, regardless of background, have an opportunity to achieve the highest health possible.

Let's assume there is a diverse group of individuals with the same health goal. In a health equality-based approach, all individuals in the group are provided the same resources to achieve the health target. In an equity-based approach, however, we acknowledge that certain individuals in the group—those who were more disadvantaged at the start—will need additional support or provisions to reach the health target. By providing additional resources to those with increased need, everyone in the group can reach the desired target.

When there is lack of health equity, we have health disparities—preventable differences in disease occurrence (how often people get the disease), health outcomes (how well those with a disease do), or treatment in one community relative to another. These differences are common among racial and ethnic minorities, and they also occur

by gender, socioeconomic status, geography, sexual orientation, and mental and physical ability.

Colorectal cancer (CRC) is an example of a disease lacking health equity in the United States. CRC cases and deaths are 20% and 40% higher, respectively, in Black compared to White individuals. In addition, Black Americans, LatinX, Asian Americans, and American Indians/Native Americans are less likely than White Americans to receive CRC screening, which we are all aware can be lifesaving.

**WE CAN ALL CONTRIBUTE TO STAMPING OUT HEALTH DISPARITIES THROUGH THREE STEPS:**

- 1** We must all acknowledge that disparities exist.
- 2** We must identify the mechanisms by which some groups are systematically disadvantaged.
- 3** We must act in situations in which we observe bias or unfair treatment.

**Action includes:**

- Sensitivity to people and patients of different backgrounds and cultures.
- Voicing concern when disparities are observed.
- Supporting public health programs and interventions that address disparities.

**Through such efforts, we can eliminate health disparities and achieve health equity for all. It's going to take all of us!**



**DID YOU KNOW?**

*Colorectal cancer cases and deaths are 20% and 40% higher, respectively, in Black compared to White individuals.*



**FOLA P. MAY, M.D., PH.D.**

Assistant Professor of Medicine, UCLA Health; Director, Melvin and Bren Simon Gastroenterology Quality Improvement Program; Staff Physician, Division of Gastroenterology, VA Greater Los Angeles Healthcare System

**MEMBER OF FIGHT CRC'S HEALTH EQUITY COMMITTEE & BOARD OF DIRECTORS**





# THE SQUEAKY WHEELS in Colorectal Cancer Research

To understand research advocacy, think of it like a furniture store, says our founder Nancy Roach.

Some groups are created to hold signs out front and let people know there's furniture for sale. But other groups are trained to work behind the scenes, nose-to-nose with the craftsmen who are designing and building the furniture. These groups make sure the furniture is actually comfortable and sturdy, and their input leads to improved and better designs. That's the role Fight CRC plays, and it sums up our Research Advocacy Training and Support (RATS) program.

"In the beginning, there were three colorectal cancer research advocates who were called upon to participate in scientific committee meetings," said Roach.

**"My vision was to have a trained group of sophisticated advocates who could make a compelling argument based on their understanding of the data, advocates who participate in the research community. That's what we've been working on, and it's happening now."**

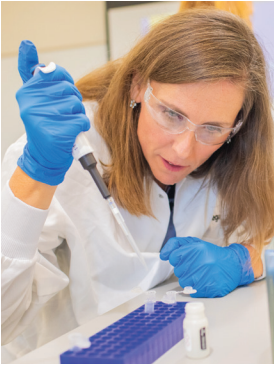
Since 2005, we have been building our team of research advocates. It's taken funding, dedication, staffing, and commitment to get where we are today. We still have a long way to go, but 15 years later, we are proud that our group of three has grown to 40. Other organizations are now asking us to help train their advocates!

## RATS

*Research Advocacy  
Training and Support*

Fight CRC's Research Advocacy Manager Reese Garcia (far left) and several of the research advocates during a lab tour





### **Check out where Fight CRC's "squeaky wheels" are serving!**

Alliance for Clinical Trials in Oncology  
 American Association of Cancer Research (AACR) Scientist Survivor Program  
 American Society of Clinical Oncology (ASCO)  
 Expert panel on adjuvant therapy for stage II/III CRC  
 College of American Pathologists (CAP)  
 Department of Defense Peer-Reviewed Cancer Research Program (DOD PRCRP)  
 Facing Our Risk of Cancer Empowered (FORCE)  
 Friends Of Cancer Research (FOCR)  
 Industry Patient Advisory Boards  
 Mercy/Trinity Hospital  
 Patient Family Advisory Council

National Cancer Institute  
 GI Steering Committee  
 Central Institutional Review Board (NCI CIRB)  
 National Coalition for Cancer Survivorship (NCCS)  
 National Comprehensive Cancer Network (NCCN)  
 National Quality Form  
 Patient-Centered Outcomes Research Institute (PCORI)  
 Ruesch Symposium  
 SWOG Cancer Research Network  
 UK Grand Challenges  
 OPTIMISTIC Study

### **What do the research advocates do?**

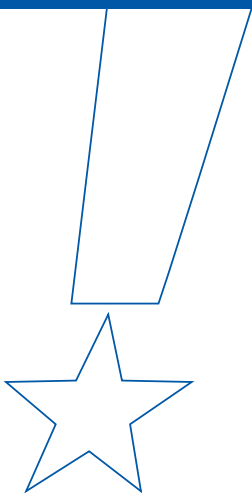
Here are a few ways we champion the patient voice:

- Weigh in about the level of detail patients want to receive about their diagnosis from their physician.
- Update technical jargon to make research easier for patients to understand.
- Explain the tone for honest and empathetic conversations.
- Offer diverse perspectives from a range of backgrounds.
- Point out specific factors that are important to patients and caregivers when clinical trials and other research studies are being designed.
- Increase patient enrollment in clinical trials by sharing recruitment information.

**LEARN MORE**

Become a research advocate and/or fund our program at [fightcrc.org/rats](https://fightcrc.org/rats).





## Catching Up with Rep. Donald Payne, Jr.



Years ago, we met Congressman Donald Payne, Jr. under unfortunate circumstances.

His father, New Jersey's first African-American congressman, had passed away from colorectal cancer at age 77 and Payne, Jr. had won a special election to take his seat. Since arriving in Washington, D.C. in 2012, he has been a relentless champion of hope for families in his district as well as the cancer community. He has co-sponsored and introduced legislation to increase colorectal cancer screening rates and remove barriers. He's quick to support policies that fund research and affordable care. And, he's been a part of chartering several initiatives at Fight CRC, like the Congressional Advisory Committee. In 2014, we awarded him with our Congressional Champion Award.

To rally us for March, Colorectal Cancer Awareness Month, we caught up with Rep. Payne to get his perspective about where things stand in D.C., why advocacy is important, and how he feels about stepping into his father's legacy and creating one of his own.

**Q When you think about all you've done to support the colorectal cancer community, what achievements mean the most to you?**

**A** My most important achievement would have to be my bill, the Removing Barriers to Colorectal Cancer Screening Act, or H.R. 1570. Even before it passed in December 2020, it was one of the most popular bills in Congress. It had been passed twice already in the House of Representatives as a part of other legislation, such as the Elijah E. Cummings Lower Drug Costs Now Act (H.R. 3), and passed a third time as a stand-alone bill.

Another achievement that means a lot to me is the work I have done to support that bill and bring more awareness to colorectal cancer. I want to make sure this deadly disease receives the proper funding, research, and attention. Recently, I helped secure at least \$43 million for the Centers for Disease Control and Prevention's Colorectal Cancer Control Program (CDC's CRCCP) because I thought these efforts were not receiving the appropriate amount of resources to continue the fight effectively.

I know there are other actions that need to be taken to combat colorectal cancer. I look forward to working with Fight Colorectal Cancer and other supporters to identify and address them now and in the future.

**Q We are celebrating with you about the Medicare Loophole Bill getting signed into law! What can we expect to see from Congress now?**

**A** I believe that because my bill is now the law, it will be easier to introduce other bills designed to decrease the mortality rate of this deadly disease. But it will not happen without the dedicated work of your organization and supporters.

**Q You're also a member of the Congressional Black Caucus and co-chair the Congressional Men's Health Caucus. How are you and your colleagues working to address health disparities?**

**A** First, we are working to increase awareness that the disparities exist. Several articles have discussed how the current COVID-19 public health crisis has been



*"I believe that because my bill is now the law, it will be easier to introduce other bills designed to decrease the mortality rate of this deadly disease."*

—REP. DONALD PAYNE, JR.



far more devastating to minority communities than White communities. That is why we included specific measures in the revised HEROES Act stimulus package to help these communities directly, including \$9.2 billion to expand health care services for underserved populations. I wrote letters to Committees and House leadership to notify them that the vaccine must be made available to all Americans in every community, regardless of income level.

Second, we are working to eliminate disparities for all medical conditions. I know that African Americans are 20% more likely to get colorectal cancer and 40% more likely to die from it than other ethnic groups, according to the American Cancer Society. I am fighting to bring more awareness to these facts and more resources for research so we can get more Black men screened for the disease, catch it early, and increase the chances of survival.

Another example concerns limb amputations. I have been fighting to increase awareness of peripheral artery disease, or PAD, because it can clog arteries and cause limb amputations if it is not treated early. These amputations occur predominantly in communities of color. I introduced legislation this year to reduce

these unnecessary amputations. These are just a few of the many actions that my colleagues and I take every day to create more equality in our health care system.

**Q Why is it important for advocates to continue engaging their Members of Congress, even if it's limited to virtual engagement, like sending an email?**

**A** It keeps the issue relevant to them. Many elected officials use public opinion to gauge the importance of an issue before they determine how to allocate time and resources to it. The more they hear about an issue, the more they figure it is important to their constituents. So advocates should continue to engage their representatives at the local, state, and national level through virtual events, polite emails, and social media posts because it demonstrates the importance of an issue, such as colorectal cancer, in their community.

**Q If your dad could see you today, what do you think he would say?**

**A** I would hope he would be proud of the work I have done to help the people of my district and the causes that matter to me. My father was a beloved Congressman here in Washington and in my 10th Congressional District of New Jersey. But he was also a hero of mine and a tremendous role model for me. He taught me the importance of

standing up for the less fortunate and fighting for equality in society. He died from colorectal cancer in 2012. That is why the fight against colorectal cancer is so important to me. I want to find new treatments and cures for colorectal cancers so other families do not have to lose their fathers, brothers, sons, and friends to this dreaded disease.

**Q In a climate full of unrest and uncertainty, you've continued to fight for hope. What encouragement would you give to our relentless champions who are also wanting to leave powerful, long-lasting, hope-filled legacies?**

**A** I think they do it every day with their example. Anyone who fights colorectal cancer or fights to bring more awareness to the disease is already a hero who establishes a powerful and long-lasting legacy for everyone around them.

But if they are looking to do more, I would say be public and proud of your fight and work against this disease. Share your experience in person or online. Show people that your drive and determination will always win the day.





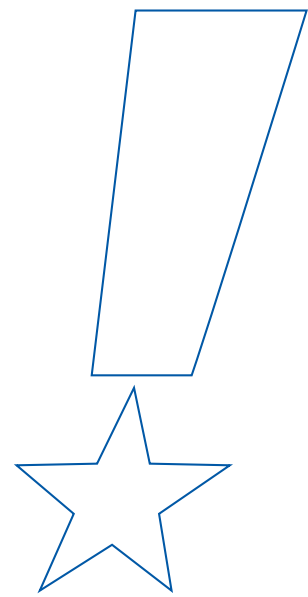
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**Your stories inspire me and serve as one of the reasons I fight so strongly for hope.**

*You are saving lives with your passion and dedication. You embody hope and you are already champions for taking on this fight in the first place. So keep fighting and we will defeat this disease sooner than you might think.*

*Be public and proud  
of your fight against  
this disease.*

**Rep. Donald Payne, Jr.**







## *Pulling Back* **THE CURTAIN ON CAPITOL HILL**

Former congressional staffer Molly McDonnell, now Fight CRC's Director of Advocacy, explains how progress is made when you share your story with lawmakers, both in person and virtually.

A little over a year ago I started as Fight CRC's Director of Advocacy. Prior to joining Fight CRC I worked as a staffer on Capitol Hill. For nearly six years, I was the person sitting across from you when you shared your story during Call-on Congress, the person reading and responding to your emails, and the person carrying your message to your Member of Congress. I met with hundreds of patient advocates

and their loved ones. During this time, I learned what was effective and what wasn't, and my goal at Fight CRC is to use that experience to help pull back the curtain a bit on how Capitol Hill works.

Early on in my tenure on the Hill, I met an advocate named Michael. Michael's son had a rare neurological condition that required frequent surgeries and close monitoring. He created his

own "Hill day" where he came to D.C. and met with his Members of Congress because there wasn't an advocacy organization for him to join. During our meeting, he shared his son's story and what more funding for medical research could mean for his son's future. Michael also asked questions—about me, about the Congressman, and about the legislative process. He stayed in touch.

We built a connection and over the next several years, we made progress. We identified sources of funding for research into his son's condition, we developed congressional champions, and we made connections with other advocates with similar needs. It didn't happen overnight and there remains a lot of work to be done, but we made progress. And it started with one person sharing his story and building a connection.

**Especially in today's challenging political environment, I know it is easy to get discouraged. But I can't stress enough how important it is for you to engage your elected officials about the issues you care about.**

Make connections with not just the office, but the person sitting across the table—the person in a role like I used to have. Trust me, they're listening.

January didn't only mark the beginning of a new presidential administration, but also the beginning of a new Congress. It's kind of like the first day of school. Dozens of "freshman" lawmakers, new Members of Congress, and a handful of Senators were sworn

in and will learn how to navigate their new workplace.

These new lawmakers will have a lot to learn, and that's where our Fight CRC family comes in. Many of them, including their staffers, will know very little about colorectal cancer. It is our job to educate them. They need to hear from you about what it feels like to receive a colorectal cancer diagnosis, even if you've told your story on the Hill or emailed already. They need to know why getting screened early is so important and what advances in treatment through medical research could mean for you and your loved ones. They need a face to go with these policies. Who better to do this than you?

Call-on Congress is a great opportunity that is just around the corner. For 14 years we have gathered advocates in Washington, D.C. to meet with their Members of Congress. With the pandemic, we know this year may continue to look different. But, what won't change is the fact lawmakers need to hear from you.

Whether virtually or in person, we need you to share your story. We want to empower you to build connections with policymakers and with your fellow advocates. I guarantee there's a staffer working in a role like I did that will connect with your story, just like I connected with Michael's. As we ramp up our advocacy efforts in 2021, I hope you'll join us.

**JOIN US**

### **2021 CALL-ON CONGRESS**

See page 32 for details and visit [calloncongress.org](http://calloncongress.org).



# NO SHAVE NOVEMBER

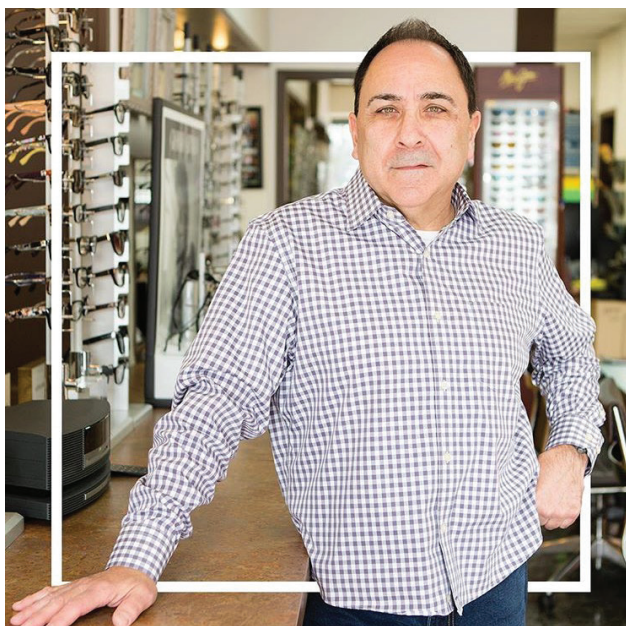
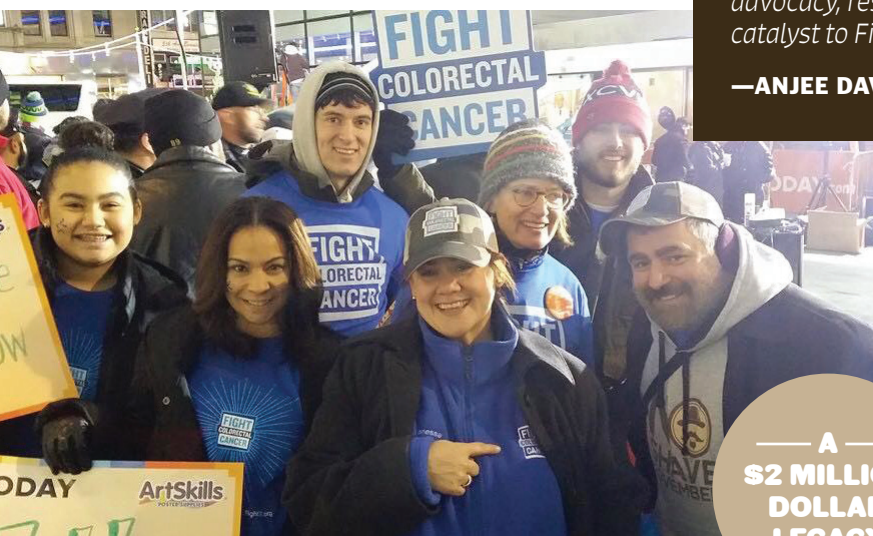
No-Shave November is one of Fight CRC's most relentless champions. Over the past five years, they have donated more than \$2.1 million!

## WHAT IS NO-SHAVE NOVEMBER?

No-Shave November is a 501(c)(3) organization founded by the family of Matthew Hill, a loving father who passed away from colorectal cancer in November 2007. The Hills saw the viral movement encouraging men and women to ditch their razors during November as a huge opportunity to keep their father's legacy alive through fundraising. Fight Colorectal Cancer is honored to be one of the nonprofits supported with dollars raised by No-Shave November.

## WHY SUPPORT FIGHT COLORECTAL CANCER?

"We at No-Shave are thrilled to be working with and donating to Fight Colorectal Cancer," said Nick Hill, one of No-Shave November's founders and board members. "It holds a personal meaning to bring awareness to the disease that took our father's life at the young age of 50. Our hope is for everyone to get involved in some way or another, to share their story, or to benefit from hearing other stories shared. We can all work together to help prevent this disease and at No-Shave, it starts with putting the razor down!"



## SURVIVOR BOB CERAGNO

and his wife Marlene host an annual "Shave-off" at his local eyewear store to raise funds and awareness about the importance of screening.

## What has Fight CRC done with the money?

In 2015, No-Shave November made Fight CRC history when they gave the largest donation we'd received to-date (\$378,650 at the time). Since then, their support and awareness has only grown. We've now received more than \$2 million from their efforts.

## WE'VE USED THESE DOLLARS TO SUPPORT PROJECTS LIKE:

- Sending survivors to D.C. so their stories can be heard.
- Funding scientists through awarding research grants.
- Hosting virtual and in-person advocacy events.
- Creating workgroups to convene researchers.
- Producing dozens of new patient resources.
- Gathering survivors and caregivers to gain a sense of community and family through Fight CRC events.
- Hosting research advocacy training to get patients engaged in the science.
- Producing this magazine!

*"We're incredibly humbled and grateful for No-Shave November's continued support. These funds have multiplied our impact in advocacy, research, and patient support. No-Shave has been a catalyst to Fight CRC's growth over the past five years!"*

—ANJEE DAVIS, PRESIDENT OF FIGHT CRC

## WE GO WAY BACK!

Over the years, we've been featured on the TODAY Show with No-Shave November (pictured left), received support from national retailers like American Eagle, and rallied large and small communities.

The Ceragnos (Bob pictured above) in New Bergen, N.J. have raised more than \$55,000 through their annual No-Shave event!

— A —  
**\$2 MILLION  
DOLLAR  
LEGACY**

## HEALTH EQUITY WEBINARS

**What's being done to increase screening rates in underserved populations?**

Replay the webinars from our community-based webinar series! More to come!



**SCAN TO WATCH**

## INDIGENOUS COMMUNITIES WEBINAR

Presented in partnership with



**SCAN TO WATCH**

## AFRICAN AMERICANS WEBINAR

Presented in partnership with



## Spanish Resources *Now Available*

We NOW have resources available in Spanish! If you or someone you know is in the fight against colorectal cancer or just needs information on screening, check out our resources!

AHORA tenemos recursos disponibles en ESPAÑOL! Si tú o alguien que conoces está en la lucha contra el cáncer colorrectal o sólo necesita información sobre la detección, revisa nuestros recursos!



## Wellness Wednesday

Have you checked out our latest Wellness Wednesday series with Karia Coleman, MSK?

Karia is a personal trainer and athletic strength coach. He will be explaining exercise research and leading us through a variety of virtual workouts this spring! Join us on social media the first Wednesday of every month (until June) and each Friday on Instagram as he teaches our Fight CRC family exercise tips and gets us ready for Climb for a Cure 2021!



# Relentless **AMBASSADORS**



## **Derek Kirkman**


"Fight CRC's Anjee Davis reached out to me when I was first diagnosed and she was a huge help. As a patient, it was terrifying to go through diagnosis and treatment, I was constantly looking for any info I could find. I'm ready to give back and share my experience to help others."

### **STAGE IV SURVIVOR**

*Alpharetta, GA*

#### **ENTERED THE FIGHT:**

6/16, Age 47

dkirkman 



## **Daniel Bloomgarden**



"My desire to help other patients and caregivers has been building since I finished treatment, but I needed more time to raise a young family, grow in my career, and better understand the reverberations of survivorship. I walked away with goosebumps after learning what Fight CRC is all about. Part of the mission is that 'No one fights alone' and I'm ready to fight for others."

### **STAGE III SURVIVOR**

*Larchmont, NY*

#### **ENTERED THE FIGHT:**

10/13/14, Age 40

dbloomgarden  





## **Courtney Maurer**

"I think forming relationships at Fight CRC is important, and it's kind of like a support system and family. I fight for others who are going through what I went through and for the caregivers. I also fight for myself since I was young when diagnosed. I want to be an advocate and spread awareness so others can prevent this cancer."

### **STAGE IV SURVIVOR**

*Overland Park, KS*

#### **ENTERED THE FIGHT:** 7/25/17, Age 29

courtneyr13  cancer\_warrior7 



## **Jelena Tompkins**

"I do a lot of sharing of information about CRC. I show what it's like to go through treatment, and what life is like after cancer on social media. It's the most exciting, easiest, and least stressful way for me to be involved. I wanted to become an Ambassador to take my involvement to the next level and connect more closely with other survivors while making a difference."

### **STAGE III SURVIVOR**

*Colorado Springs, CO*

#### **ENTERED THE FIGHT:** 5/25/16, Age 34

colorado.jelena  Survivor\_Jelena 



## **Greg Vaughn**



"I fight for those who need hope, encouragement, and the warrior mindset to win another day. I'm very passionate about not letting stage IV colorectal cancer keep me from enjoying life. I'm a pilot, a professional photographer who chases storms, a former professional cyclist, and I've run 97 marathons, and 17 ultra-marathons of 100 miles or more. I'm not about to let cancer scare me or keep me from doing what I love. I strongly believe that by sharing my story and experiences, I will encourage others to stay strong and never give up their own fight."

### **STAGE IV SURVIVOR**

*Overland Park, KS*

#### **ENTERED THE FIGHT:**

10/20/17, Age 48

gregvaughn913  



## **Melvin Fernandes**

"I am four years out from my diagnosis, and I feel it is time to spread the word about colorectal cancer. I want to educate people about this disease and help prevent deaths. I fight for those that can avoid or prevent getting this disease."

### **STAGE III SURVIVOR**

*Lyndhurst, OH*

#### **ENTERED THE FIGHT:**

11/17/16, Age 42

Melvin.fern  Em\_effor 



## Here they are!

Meet the survivors, caregivers, loved ones, and medical professionals who are representing our Fight CRC family this year!





### Joe Bullock

"I am a fighter! I fight to spread awareness about colorectal cancer. Early detection is crucial, a colonoscopy is important at age 45. My survivorship is what gives me hope. I'm involved with Fight CRC to promote research so others can survive."

#### STAGE III SURVIVOR

*Durham, NC*

**ENTERED THE FIGHT:** 5/29/18, Age 50

Jbullock114  




### Scott Oomen

"I want to make people aware of the dangers of not getting screened and help them understand the symptoms that should lead to getting tested. Because Fight CRC has been instrumental in my recovery, I wanted to join them and become a national voice for early detection and testing."

#### STAGE III SURVIVOR

*Portage, MI*

**ENTERED THE FIGHT:** Age 44

Scott\_oomen 




### April Schack

"I fight for my family. When I first got sick, I was scared and had no idea what to expect. While going to treatments and building confidence, I met so many patients who were new and scared. It broke my heart and I don't want anyone to ever feel alone."

#### STAGE II SURVIVOR

*New Castle, DE*

**ENTERED THE FIGHT:** 9/18, Age 37

Aprils01 



### Edward Gallagher

"I fight for the rights of all people; medical care is a human right. I've survived more than 55 rounds of chemo, and I want to show how there is life after a diagnosis. Cancer research gives me hope and I've become a relentless champion to provide optimism and because Fight CRC's work in immunotherapy has directly affected my life."

#### STAGE IV SURVIVOR

*Arlington, VA*

**ENTERED THE FIGHT:** Age 64

goodhikers1 



### Keilah Goff

"I fight for myself, everyone who currently fights, and all who could face a colorectal cancer diagnosis in the future. I want to educate the public on good health and dietary habits and proper screening to avoid the disease. I became an Ambassador to support research, encourage other patients to fight, and provide information on the best treatments available. I don't want anyone else to face the devastating diagnosis I was given three years ago."

#### STAGE IV SURVIVOR

*Dunn, NC*

**ENTERED THE FIGHT:** 12/30/17, Age 51

KGCarolinaGirl  Carolina\_Girl88 



### Dr. Carmen Fong

"I've joined the relentless champions of hope because I believe we should never give up on the fight for a cure or the access and funding needed to prevent colon cancer, both of which, I believe, are achievable in our lifetime. I fight for patient access to health care, patient dignity, and autonomy throughout the process."

#### COLORECTAL SURGEON AT MOUNT SINAI

*New York, NY*

# BASSADORS






### Linda Graffin

"I fight for my sister who passed away from colon cancer in 2017 and I fight for myself. I had stage II colon cancer but it would probably have been stage IV if not for her. I believe colorectal cancer should have the glitz of Breast Cancer Awareness Month in October. My passion is to raise awareness about disparities in access to care and the fact this disease can happen to young people."

#### CAREGIVER & STAGE II SURVIVOR

Deerfield, WI

**ENTERED THE FIGHT:** Her sister was diagnosed in 2/15 at age 46; Linda was diagnosed in 5/15 at age 42

gunsolusgraffin 





### Lisa Johnson

"I fight for the former 26-year-old me who felt so alone and lost in a crowded world after an early-age onset diagnosis, and for the 27-year-old me who felt scared after a recurrence. Today, there is someone who is feeling the exact same way. My 'cure' was to pay it forward and do whatever I can for our cause. I'm not sure WHY I survived this beast, but I did and I want to spend every day fighting for change, conversation, awareness, and all those this disease has and will-undoubtedly-touch. I want those affected to know they are not alone and those who have gained their blue wings to know we will continue the fight for them."

#### STAGE III SURVIVOR

Rivesville, WV

**ENTERED THE FIGHT:** 4/28/10, Age 26

CancerSheek  



### Evan White

"Being a relentless champion of hope is all about being a beacon of light for others. No matter how deep the valleys or how dark the struggles, we will continue to inspire others, stay positive, and live our lives to the fullest. I'm involved with Fight CRC because colorectal cancer isn't just my fight and I hope my story and my experiences will give others hope."

#### STAGE IV SURVIVOR

Keller, TX

**ENTERED THE FIGHT:**

7/10/17, Age 24

realevanwhite  

#### CAREGIVERS Jacksonville, FL

**ENTERED THE FIGHT:**  
Tiffany was diagnosed  
11/18, Age 32




### Tamara Shaw

"I fight for my twin sister and I want her legacy to continue. I want to help others going through this journey like she did. I want to advocate on her behalf. It is my family's mission to help make others aware of the seriousness of this cancer."



### Gwendolyn Bryant

"I strongly believe the screening age should be lowered for early detection. My 34-year-old twin daughter passed away in March 2020 from colon cancer and more young adults are being diagnosed. Tiffany was a nurse and advocate, she shared her story to help others. Her impact encouraged others to get screened and her legacy will live on. Our family will continue to FIGHT!"

gwendolyn.bryant 



### Jonathan Ortiz

"I fight for my wife's legacy, and everyone out there who is fighting colorectal cancer. She was only 32 when she was diagnosed and passed away in 2020. I want to bring more awareness to this disease, to the importance of early screenings, and to help those who are fighting to get the appropriate treatment they need. To me, being a relentless champion of hope looks like having a part in making sure no one else has to go through what I am. Fight CRC gives me a purpose outside of my home."

# Relentless **AMBASSADORS**



## **Lynne Ireland-Knight**

"We were like deer in the headlights when my son Jordan was diagnosed with stage IV colon cancer. It was uncharted territory. As he continues his fight, I want to stress the importance of early detection. No one is immune. I think the work Fight CRC does is incredibly important and invaluable to patients and their families. I'm here to offer comfort and hope when it is needed, realizing most of us can make a huge difference in others' experiences."

### **CAREGIVER**

*Bethel Park, PA*

**ENTERED THE FIGHT:** Jordan was diagnosed in 9/18 at age 29

lynneik



## **Richard Hays**

"I want to help others so they will not suffer. Getting involved with Fight CRC showed me I'm not alone. I'm getting involved because it allows me to give back using my past experience in fundraising. Fight CRC has consistently communicated goals, programing, and future initiatives—giving its donors commitment to the cause."

### **STAGE II SURVIVOR**

*Harwood, MD*

**ENTERED THE FIGHT:** Age 61



## **Rachel Moore**

"I'm a wife, mother, and business owner whose life was flipped upside down with a very unexpected diagnosis. I work very hard to not only spread my message of early detection on my blog (shitsandgigglesink.com), but also the power of positivity. I believe my outlook and strong sense of hope have helped my treatments be successful. I also come from a unique story in that of my high school graduating class of 250 students, five of us have been diagnosed with CRC all under the age of 40. We are currently working to find out why this unusual and troubling situation has occurred."

### **STAGE IV SURVIVOR**

*Overland Park, KS*

**ENTERED THE FIGHT:** 3/24/19, Age 39

the\_moore\_you\_know\_kc



## **Carole Motycka**

"After I was diagnosed, I lost purpose and the grief was overwhelming. I yearned for a community that understood what it felt like to be in the prime of life, the best shape ever, and be struck with such a blow. I felt alone, I didn't want anyone to experience that type of pain. I knew I wanted to engage in a community of people who would listen, understand, and help me find my new purpose. I am a relentless champion of hope to lead people to this community so they never feel alone."

### **STAGE IV SURVIVOR**

*Wolcott, CT*

**ENTERED THE FIGHT:** 4/9/16, Age 42

swtcareline ctycka



## **Edward Stratton**

"When I was diagnosed, I knew nothing about colon cancer; I knew very little about any sort of cancer treatment in general. I learned most things through the stories and experiences of others. For that reason, I want to help with public awareness. I don't feel that my story is unique, and that is specifically why it needs to be told."

### **STAGE IV SURVIVOR**

*Ballwin, MO*

**ENTERED THE FIGHT:**

4/1/19, Age 60

edstratton



## **Beth Kornegay**

"I fight for my son and my son's future children so the word 'cancer' will not be something they need to worry about during their lifetime. Screenings are so important because they save lives—they saved mine. I was diagnosed 12/27/13 and remember that lost feeling, so I want to lift the spirits of newly diagnosed patients and those undergoing treatments to provide them with hope. I've connected with other local survivors and it has meant so much."

### **STAGE III SURVIVOR**

*Shawnee, KS*

**ENTERED THE FIGHT:** 12/27/13, Age 50



# What I Wish



Over the course of four years, Fight CRC's Patient Education and Research Team undertook a big research project. Between 2015–2018, we hosted six focus groups with 79 survivors, caregivers, and loved ones who bravely answered these two questions:

## **WHAT INFORMATION DO YOU WISH YOU HAD AT DIAGNOSIS?**

## **WHAT INFORMATION DO YOU NEED NOW?**

The relentless champions who participated in this research study (officially named “*Priorities of Unmet Needs for Those Affected by Colorectal Cancer: Considerations from a Series of Nominal Group Technique Sessions*”) gave honest, real, and fearless feedback about the top unmet needs of the patient community.

Here's the Top 10 themes that emerged (in no particular order):

**1**  
**FAMILY & CAREGIVER SUPPORT**  
*that recognizes unique aspects of caring for a CRC patient.*

**2**  
**UNDERSTANDING OF SIDE EFFECTS**  
*at time of diagnosis (chemotherapy, medical marijuana, medication interactions, and ostomy support).*

**3**  
**INCREASED COMMUNICATION**  
*and coordination with care teams, especially patient navigators.*

**4**  
**BETTER EXPLANATIONS**  
*of the intricacies of a cancer diagnosis and care.*

**5**  
**ACCESS TO CRC RESOURCES**  
*particularly for those in a specific age group, gender identity, cancer stage, race/ethnicity, etc.*

**6**  
**MENTAL & BEHAVIORAL SUPPORT**  
*including counseling and therapy.*

**7**  
**UNDERSTANDING OF PALLIATIVE CARE**  
*medication adherence, maintenance therapy, and ending treatment.*

**8**  
**TREATMENT & SURVIVORSHIP CARE**  
*access to plans, supportive care beyond treatment, tools to utilize complementary health and manage cancer as a chronic disease.*

**9**  
**EDUCATION AROUND GENETICS**  
*clinicians to provide information and offer genetic testing.*

**10**  
**HELP WITH UNDERSTANDING**  
*research, risk/recurrence, and legal support/employment.*

Our team is hard at work sharing this information with medical professionals and developing resources to meet these needs. Those who participated in the research study have left a powerful legacy that is helping change the future of care! The full findings of this study will soon be published in the National Comprehensive Cancer Network Journal. Thank you to everyone who participated!

## **STUDY AUTHORS**

**Sharyn Worrall, MPH, Andrea J Dwyer, BS, Reese Garcia, MPH, Keavy McAbee, MPH, Anjelica Q Davis, MPPA**

**Medical  
Providers:**

**Looking for FREE, credible, medically reviewed resources to distribute to your cancer center or support group?**

Look no further! You can request bundles of *Beyond Blue*, mini magazines, awareness materials and more. Browse our online catalog at [shop.fightcrc.org](http://shop.fightcrc.org), or email [estore@fightcrc.org](mailto:estore@fightcrc.org) to get started!

*Resources available in English & Spanish!*



**SCAN TO BROWSE & ORDER**



## Looking for an easy way to get involved at Fight CRC?

### Become a Resource Champion!

Resource Champions are dedicated volunteers who take critical awareness and patient education materials into their local communities. Resource Champions are survivors, caregivers, medical providers—anyone who wants to raise awareness and support patients in a very practical way!

As a Resource Champion, you will receive up to four FREE mailings per year including:

**BEYOND BLUE MAGAZINE (RELEASES IN SPRING & FALL):** supports patients and caregivers with valuable information and stories of inspiration.

**PATIENT EDUCATION BOXES:** include mini magazines, brochures, and fact sheets about topics important to those diagnosed with colorectal cancer.

#### HERE'S HOW IT WORKS:

- 1** You'll receive a package of free patient resources at your doorstep.
- 2** Share the resources with friends, family members, and people at your doctors' offices. (Mask up if you leave home!)
- 3** BONUS: Post on social media as you're distributing and tag @FightCRC.

*It's super easy, but really effective! Help us extend our reach to the people who need resources the most and become a Resource Champion! Sign up online to get started at [fightcrc.org/resourcechampion](http://fightcrc.org/resourcechampion).*





## CALL ★ ON ★ CONGRESS

**MARCH 2021 & JUNE 2021**

*Virtual & In Person (hopefully)*

New year, new look. Call-on Congress is back and in 2021, we are doing things a little differently.

Call-on Congress 2021 will continue to celebrate the strength and resilience of our community, but this year we are combining virtual and in-person events to allow for even more relentless champions of hope and more time for exciting activities!

Starting in March we will offer virtual sessions focused on empowering you to share your story, understand our CRC policy priorities, practice meeting with legislators, and more! We are hopeful for this to lead up to celebrating and connecting as a community in Washington, D.C. in June (pending health guidance regarding COVID-19).

Visit [calloncongress.org](https://calloncongress.org) to get event announcements and sign up!

## CLIMB ★ FOR A ★ CURE

**SUMMER 2021**

Climbing a mountain requires the same grit and determination it takes to face your own cancer diagnosis or the diagnosis of a friend or loved one.

COVID-19 transformed our annual Climb into something even better than a one-day event! In 2020 we opted for a virtual event in lieu of an in-person Climb and more than 800 participants from 47 states raised over \$250,000 and took 10 million steps cumulatively!

This summer we're climbing for the cause again. We hope you'll join us to get active, push yourself, support others, and make an impact on the lives of the relentless champions of hope!

Visit [fightcrc.org/climb](https://fightcrc.org/climb) for the most up-to-date event details.



### **3rd Annual International Early-Age Onset Colorectal Cancer Symposium**

*In collaboration with Dr. José Perea  
from the Jiménez Díaz Foundation  
University Hospital*

Join the global community as we come together to zero in on early-age onset colorectal cancer. In addition to convening researchers from around the globe, we will also bring together patients and advocates to share first-hand perspectives.

During the 2021 Symposium, attendees worldwide will continue multi-disciplinary, action-based discussions in order to advance research on the causes of EAO CRC and practice-based strategies for clinical public health.

For more information, visit  
[www.fightcrc.org/eaocrc](https://www.fightcrc.org/eaocrc).

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

**Genentech**  
*A Member of the Roche Group*

**NO SHAVE  
NOVEMBER**



# addressing end-of-life care **AND** conversations

## Talking about death and dying is hard. It can be triggering and difficult.

Licensed clinical social worker Darah Curran, MSW, LCSW, OSW-C, has been helping our relentless champions of hope face these tough conversations. If you're wondering how to approach the subject, here are a few ideas:

### REFLECT ON YOUR WISHES

Ask yourself questions. Spend time thinking about what you hope the end of life looks like for you. This can give you not only a sense of control, but it also relieves family members from making hard decisions after the loss and allows them to focus on processing their grief. Remember: there is no right or wrong!

- With whom do you want to spend time? Do you want co-workers, friends, and family members coming to see you? Or would you prefer to be more private?
- What do you want to do? Do you hope to knock out your bucket list and travel? Or slow down and spend time at home?
- Who do you want helping to make decisions? What medical interventions would you hope to access or avoid?

- What do you want your funeral, service and/or celebration of life to look like?
- What do you hope your legacy becomes? What are your values and the accomplishments you're most proud of? What do you hope to impart on others around you? How do you hope to express this?

### PUT THINGS IN WRITING

Putting your wishes in writing can reduce a lot of distress. Once you've taken time to reflect, write them down so they can be more easily shared when you're ready.

- Journal (or audio files): Capture your meaningful memories, thoughts, and wishes.
- Advance Directives: You can create an advanced directive at any point in your life. Each state handles them differently, search online for what's required in your state. (If you move states, you'll need to update your advanced directive.) This is a document that outlines things like who your decision maker will be if you cannot make decisions for yourself and health care instructions, like do or do not resuscitate.
- Goals of Care: This applies to patients facing a specific medical situation. Goals of care help the medical team and family make decisions. Conversations may change and evolve based on your medical information, prognosis, quality of life, etc.

### COMMUNICATE YOUR THOUGHTS

It's never easy, but communicating your end-of-life wishes is an important part of life.

- Have conversations sooner versus later. If you begin to engage in these difficult conversations before there is an acute situation or crisis, the associated emotions and loss may feel less overwhelming for both you and your loved ones.
- It may be easier to begin the conversation with the more concrete aspects of care. Share your advanced directive and other wishes you've written down.
- Be sensitive to each family member's religious and cultural considerations.
- Accept associated tears and emotions. Consoling one another through emotional suffering can deepen connections and allow for healing.



**SCAN TO WATCH**

Use your smart phone and scan to watch the full presentation, Addressing Taboo Topics: End-of-Life Care.



**TIPS BY Darah Curran, MSW, LCSW, OSW-C**



# HONORING SOMEONE SPECIAL

## **Every day, we receive donations from people who are building a legacy.**

The dedications always make us smile. Sometimes they say things like, "To all the warriors and those affected by CRC." Other times, we read that donations have been made to honor people like "Mom," "Dad," "Grammie," and "Grandpa."

Below are the names of individuals who inspired a donation to Fight Colorectal Cancer in 2020. Thank you for trusting us with your dollars. We promise to use each one to keep building up the relentless champions of hope.

Adrian Richardson	Arnie Shore	Carmen	David Ashton	Eddie Derwin	Harley Dwight
Alan & Jay Broddon	Arthur Sacks	Blackham Rindfleisch	David Burnett	Edie Deering	"Bud" Boone
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		Dave Blatchford	Ed Stratton		



*Make sure your champion's name is listed!  
Visit [give.fightcrc.org](http://give.fightcrc.org) or call 703-547-1223 to make a donation.*

# Memorial DONATIONS

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





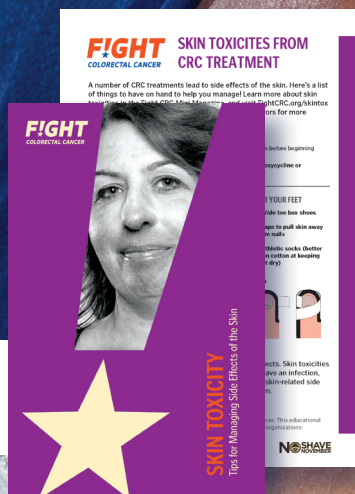
MELISSA BAHR  
Stage III Fighter

**FIGHT**  
COLORECTAL CANCER

## How do I manage chemo rash?

Skin toxicity, also known as “chemo rash,” is a common side effect for patients with colorectal cancer. Luckily, there are ways to manage and lessen the symptoms of skin toxicity.

Skin toxicity resources are available for free in Fight Colorectal Cancer’s resource library. Find them at [fightcrc.org/skintoxicity](http://fightcrc.org/skintoxicity).



[fightcrc.org/skintoxicity](http://fightcrc.org/skintoxicity)