

BEYOND BLUE

A Biannual Update For Those In The Fight Against Colorectal Cancer

**THE
RESEARCH
ISSUE**



SURVIVING STAGE II CRC

Shannon Davis

wife of Rep. Rodney Davis (IL)



**WHAT DOES
IT MEAN
TO FUND
RESEARCH?**

**WHAT FOODS
IMPACT
COLORECTAL
CANCER?**

**CONVENING
THE RESEARCH
EXPERTS**

**RESEARCHERS:
THE CANCER
DETECTIVES**

**RESEARCHER
PROFILE:
DR. EDITH
MITCHELL**



ABOUT FIGHT COLORECTAL CANCER



OUR MISSION

Fight Colorectal Cancer envisions victory over colon and rectal cancers. We raise our voice to empower and activate a community of patients, fighters and champions to push for better policies and to support research, education and awareness for all those touched by this disease.



© Photo by Evan Cantwell

MEDICAL ADVISORY BOARD:

Dennis J. Ahnen, M.D.
University of Colorado Hereditary Cancer Clinic

Al B. Benson III, M.D., FACP
Northwestern University

Nancy Baxter, M.D., FRCS
St. Michael's Hospital, University of Toronto

Dustin Deming, M.D.
University of Wisconsin Carbone Cancer Center

Dan Dixon, Ph.D.
University of Kansas Cancer Center

Richard M. Goldberg, M.D.
Ohio State University Medical Center

Carolyn Grande, CRNP, AOCNP
University of Pennsylvania

David Greenwald, M.D.
Mt. Sinai Hospital

Axel Grothey, M.D.
Mayo Clinic College of Medicine

Heather Hampel, MS, CGC
Ohio State University Comprehensive Cancer Center

Jean S. Kutner, M.D., MSPH
University of Colorado Hospital

Heinz-Joseph Lenz, M.D., FACP
University of Southern California

Paul J. Limburg, M.D., MPH
Mayo Clinic

John Marshall, M.D.
Georgetown University Medical Center

Howard McLeod, Pharm.D.
Moffitt Cancer Center

Neal J. Meropol, M.D.
Case Western Reserve University

Edith Mitchell, M.D., FACP
Thomas Jefferson University

Nicholas Petrelli, M.D.
Christiana Care Health System

Leonard Saltz, M.D.
Memorial Sloan-Kettering Cancer Center

Daniel J. Sargent, Ph.D.
Mayo Clinic College of Medicine

Joel E. Tepper, M.D.
University of North Carolina School of Medicine



To receive the latest edition of Beyond Blue via email, please visit us at:

FightColorectalCancer.org/SignUp

Disclaimer: The content of this issue was medically-reviewed. All content was written, produced and edited by Fight Colorectal Cancer. The information and services provided by Fight Colorectal Cancer are for general informational purposes only. The information and services 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.



 @damitjanet66
Caregiver to this stage IV patient



 @megan_n_lambeth
Caregiver to this CRC patient



 @oliver_ke
Stage IV survivor



 @bambie1212
Caregiver posting in memory of Steve



 @aarandamos
CRC researcher studying nanoparticles

LETTER FROM THE PRESIDENT

As a cancer patient, you hear and see the words, “support research” but what does that mean? You can’t just knock on the door of a laboratory to get involved — but maybe you should! This past year at Fight CRC, we DID!

Over the last decade, Fight Colorectal Cancer has led the way alongside a community of CRC activists demonstrating the power of pushing the research community and policy makers to make patient-centered choices. When you hear us say “support research directly,” it means we fund grants to scientists. But we also “support research” by training advocates to participate in the research process and ensure patient voices are heard. It’s our commitment to see a seat at the table representing YOU when research decisions are made.

It takes sustained commitment, relationships and preparation for patients to contribute in meaningful ways. Fight CRC is committed to this effort and we need YOU to join us.

First – be your own advocate for health and recovery. Use our resources, both in this magazine and on our website, to get well. And then, get involved! We’re leading the way for research advocates to be engaged in this enterprise. One of our founders and beloved fighters, Kate Murphy, once said,

“Research can answer interesting but irrelevant questions, provide statistically significant but clinically insignificant results ... but in the end, does it matter to patients? Researchers can lose sight of the real goals, and we can keep them honest. The very presence of advocates can make a difference. Not only does my face and my story inject reality into the cancer research enterprise, it seems to add some sense of urgency.”



Kate Murphy

If you’re like Kate and a devastating diagnosis led you here, join us in making a difference. Use this issue of Beyond Blue to get educated and informed. There is a place for everyone at the research table and the time is now.

Sincerely,

Anjee Davis
 @AnjeeDavis

Advocates: We fight for you! Show us your strength and post a **#StrongArmSelfie** on Twitter or Instagram.



PATIENT RESOURCES

MEET AN EXPERT: HANDLING GRIEF

Sara Goldberger, MSSW, LCSW-R

Sara Goldberger is the Senior Director of Programs at Cancer Support Community (formerly Gilda's Club and The Wellness Community). She's been an oncology social worker for over 26 years. Sara saw the loss of control, isolation and fear that can accompany a diagnosis first-hand after many of her family members, and later on she herself, was diagnosed with cancer. She works often with cancer patients, family members, friends and caregivers experiencing a range of difficult emotions – especially when it comes to grief. She offers this advice:

1. Everyone's grief is unique to them; there is no script you can follow.
2. It takes time to grieve for someone you loved. There is no set amount of time. Be patient with yourself and know that it will get better over time.
3. The five stages of loss (denial, anger, bargaining, depression and acceptance) are not linear stages to move through in a specific order. You may experience only some of them or move back and forth from one to another.
4. Take care of yourself. Don't neglect your health. Try to find some joy in every day. It is good to continue to do the things you enjoy.
5. It can be helpful to speak with others either one-on-one or in a support group who have been in a similar situation or with a professional counselor or member of the clergy.

“After five years as an oncology social worker, I myself was diagnosed with cancer. My understanding and commitment deepened. I continue to be inspired and motivated by the lessons I learn from the people I encounter through my work about living life fully and purposefully every day.”



Need to talk? Fight Colorectal Cancer has partnered with Cancer Support Community's Cancer Support Helpline to provide a live counselor ready to assist you with a variety of cancer-related concerns – including grief. Call **1-877-427-2111** from 9 a.m. – 9 p.m. ET Monday through Friday to get live assistance. The call line is available in English and Spanish.



RESOURCES FOR YOU:

- **Listen:** Sexual health and intimacy podcasts
- **Watch:** Colorectal cancer research webinar
- **Get:** Tips and tools for managing skin toxicity
- **Download:** iCancerHealth app
- **Read:** Understanding your tumor type fact sheet

Get all of these resources and more NOW: FightColorectalCancer.org/Resources



FightCRC.org



Toll-free Resource Line: (877) 427-2111



Facebook.com/FightCRC



Twitter.com/FightCRC

TOP 10 LIST

What Foods, Vitamins and Drinks Impact Colorectal Cancer?

Bacon causes cancer? Coffee prevents it? Here's the truth (science) behind the "buzz."

by Sharyn Worrall; medical review by Tim Byers, M.D., MPH, University of Colorado

- 1 Coffee** – There is hope! Study showed stage III patients who drink 4+ cups of coffee daily may have lower risk of CRC recurrence and mortality (Journal of Clinical Oncology, Nov 2015).
- 2 Vitamin C** – No reliable studies show a clear positive or negative affect on CRC in humans.
- 3 Red Meat** – Be balanced. Risk of CRC increases from 5-6% for those who eat 100gm of red meat or 50gm of processed meats daily, (Lancet Oncology, Oct 2015). About the size of a quarter-pounder or 1 hot dog, respectively.
- 4 Garlic** – Thumbs up. The World Health Organization suggests 1 clove daily for good health. More garlic may mean lower CRC risk (NCI, 2008). Anti-cancer benefits widely recognized.
- 5 Vitamin D** – It's complicated. Reports are mixed and unclear, suggesting a complex relationship with potential prevention benefits. Don't forget SPF when getting vitamin D from the sun!
- 6 Antioxidants** – Can't go wrong with fruits and veggies. Studies on antioxidants have unclear evidence related to CRC prevention and survivorship.
- 7 Fiber** – Bulk up! Insoluble fiber (bran, veggies, whole grains) is linked with cancer protection; 10g of dietary fiber (including oats, beans, apples) daily reduces CRC risk by 10%.
- 8 Green Tea** – May lower cancer risk and recurrence according to a number of studies.
- 9 Beer and Wine** – Moderation is key. Drinking 2+ beers daily could increase CRC risk (Cancer Causes Control Journal, April 2015). Red wine, however, may have anticancer properties.
- 10 Folic Acid and Folate** – Research shows folate (dark leafy greens, citrus fruits, and lentils) prevents CRC, whereas the synthetic form of folate, folic acid (found in supplements), increases CRC risk.



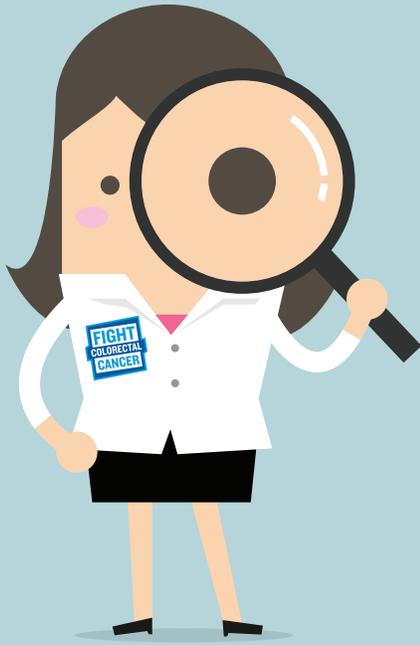
Get 3 bonus tips & more on the blog!
[FightCRC.org/Top10Foods](https://fightcrc.org/Top10Foods)



Facing a Food Fight?

Unsure of what you can eat? Feeling alone? Need tips from others who've been there? Join our Online Support Community hosted by Inspire to talk to others who've been there: [FightCRC.org/Inspire](https://fightcrc.org/Inspire)

Inspire together we're better™



THE CANCER DETECTIVES

SCIENCE NEEDS PATIENTS TO SUCCEED

By Roy Harryman

A cancer cell, like a shadowy thief, can live undetected by the body's immune system. Although in many cases the disease makes itself known, it still has a way of being elusive.

But take heart: Fight Colorectal Cancer is working with cancer cops – aka cutting-edge researchers – who are on the beat in a global effort to defeat cancer. According to the American Association of Cancer Research (AACR) Foundation, “The goal of studying cancer is to develop safe and effective methods to prevent, detect, diagnose, treat, and, ultimately, cure the many diseases we call cancer.”

A tremendous amount of work has been done already. The term “cancer research” is as broad as the types of cases we see on the nightly news. Each case is an entry into the body of evidence being accumulated to see cancer busted. Not

unlike finding a thief, cancer research takes time, dedication, collaboration and funding to crack the case.

The iconic imagery of cancer research includes bubbling beakers and scientists in lab coats peering into high-powered microscopes. And this is correct;

however, it doesn't end there. Today cancer researchers look at the entire patient experience from pre-diagnosis to survivorship.



Our Medical Advisory Board members study all aspects of colorectal cancer; meet them at: FightCRC.org/MAB

Patients willing to participate in all types of research studies are imperative for progress to continue. This is especially critical within drug development research.

From the Microscope to the Patient

Drug development research begins in the lab and is called basic research. Successful experiments move into carefully supervised clinical trials – the phase where patient treatments get involved. For drug research to advance into clinical trials, positive results in the lab must be attained through three rigorous phases – a process that can take up to a decade. Fewer than one percent of drugs cross the finish line.

Within clinical trials, three additional phases are required to evaluate multiple aspects of a drug between healthy and non-healthy patients.

The Many Aspects of Cancer Research

- Drug Development
- Prevention
- Side Effects
- Psychosocial Support
- Survivorship



FightCRC.org



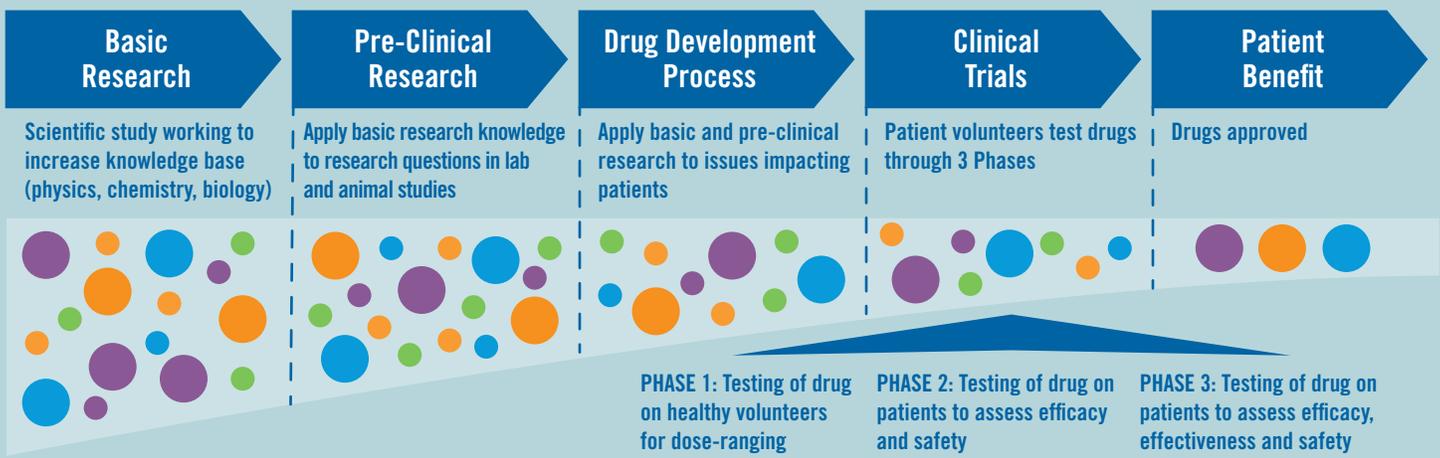
Toll-free Resource Line: (877) 427-2111



Facebook.com/FightCRC



Twitter.com/FightCRC



In clinical trials, researchers want to discover:

- Does the drug increase patients’ survival rates?
- How does it impact survivors’ quality of life?
- Are there side effects?

A drug company can request FDA approval only if a trial reaches phase 3. Once a drug hits the market, data is recorded from thousands more patients to gauge effectiveness – the process of research and evaluation is ongoing.

The Detours

Research may sound like a step-by-step process, but – like the pursuit of that stealthy thief – it’s messy and fraught with detours:

- In the United States it takes an average of 12 years for a drug to move from the lab to the pharmacy.
- The chance for a new drug to make it to market is 1 in 5,000.
- Trials may be restricted to a fixed number of patients or filtered by specific medical conditions.
- Studies may be limited geographically.

But this is not reason for despair. It’s the nature of science. Some of the greatest discoveries have resulted from initial failures or situations where great perseverance was required.



Congress is working on a bill called the 21st Century Cures Act that would expedite the drug approval process.

In the world of criminal justice, prosecutors prepare evidence with the goal of discovering truth. When it comes to cancer research, the courtroom is the clinical trial, which means beating cancer depends on patient participation. Consider yourself a witness.

Missing: Participants

Fewer than 5% of all cancer patients in the United States participate in clinical trials. The number is striking when compared to pediatric cancer research: 50% of children through age 14 have participated in trials. That level of involvement has led to dramatic progress, with more than 75% expected to become long-term survivors.

To improve clinical outcomes for colorectal cancer patients and find better treatment options, more patients will need to participate in clinical trials – researchers can’t unlock the cases without witnesses or clues.

The medical and advocacy communities are working to reduce the challenges patients face when considering clinical trials, as finding a trial requires persistence. Each one has a specific list of requirements to participate. Comparing trials is not “apples to apples.”



LINDSEY MOTLEY - STAGE IV COLON CANCER FIGHTER

Stage IV colon cancer fighter Lindsey Motley explained what she considered before joining clinical trials: “There were three things that we took into consideration: quality of life, location and travel and

the data and phase of each trial.” Trials offered an option for Lindsey after she’d exhausted all standard treatment therapies. Her participation brought attention to the importance and need of all patients, at any stage, to consider participating. “You just have to go with your gut and remain hopeful. Know that while in the end it might not be successful for you, you are paving the way for others regardless of what happens.” Her legacy lives on through her choice to advance the science no matter the outcome.

While the barriers are very real and the system to join a clinical trial can have its challenges, experts say patients should not let that deter them from working with their medical teams to find local or national clinical trials.

“Clinical trials are extremely important for patients — the care people receive in clinical trials can actually be of higher standards and quality than the standard and approved care,” said **Andrea (Andi) Dwyer, Director of Health Promotion at Fight Colorectal Cancer.**

Closing In on the Case

The good news is that participation in trials has led experts to better treatment options for patients. Patients involved in research from multiple disease states, including colorectal cancer, are seeing exciting

results as experimental research and groundbreaking discoveries continue. Trials provide both patients who do and don’t survive an opportunity to leave a lasting mark on the future.

Unprecedented collaboration amongst cancer research experts, policy makers and funders is taking place around the globe. More than ever before, cancer research has a bright spotlight on it with individuals like Vice President Joe

Biden and technology guru Sean Parker funneling focused expertise and resources toward the issue.

In cancer research, there is a place for everyone at the table ... or the courtroom.

“Although everyone longs to hear the words ‘case closed,’ victory over cancer will require tenacity,” said Anjee Davis, president of Fight Colorectal Cancer. “It’s a sustained commitment from all who have a stake, especially patients, but that’s what it’s going to take to find a cure.”

Sources:
www.ncbi.nlm.nih.gov/pmc/articles/PMC2435316/
medicinenet.com
<http://www.cancer.net/navigating-cancer-care/how-cancer-treated/clinical-trials/about-clinical-trials>



CHANGE LIVES. SUPPORT RESEARCH.

- 1 Donate funds toward Fight CRC’s research grants
- 2 Participate in a research study or clinical trial
- 3 Share your story with us if you’re on a clinical trial to encourage other patients
- 4 Ask your members of Congress to support bills for research funding
- 5 Become a research advocate

Get details of each of these opportunities at:

[FightCRC.org/Research](https://fightcancer.org/research)

FIRST STEPS

To find a clinical trial, get started by searching here:

- **Fight Colorectal Cancer**
[FightCRC.org/ClinicalTrials](https://fightcancer.org/ClinicalTrials)
- **National Cancer Institute**
cancer.gov/about-cancer/treatment/clinical-trials
- **Marti Nelson Cancer Foundation**
canceractionnow.org
- **U.S. National Institutes of Health**
clinicaltrials.gov



[FightCRC.org](https://fightcancer.org)



Toll-free Resource Line: (877) 427-2111



[Facebook.com/FightCRC](https://facebook.com/FightCRC)



[Twitter.com/FightCRC](https://twitter.com/FightCRC)

Profile of a Cancer Detective

Dr. Edith Mitchell, a pioneering cancer researcher at Thomas Jefferson University in Philadelphia, has been at the forefront of the cancer fight for decades. She was recently named one of 28 experts to provide input on Vice President Joe Biden's Cancer Moonshot Initiative as part of the Blue Ribbon Panel. Dr. Mitchell is a practicing clinician widely known for her work in fighting cancer disparities and colorectal cancer research. She appeared on EBONY Magazine's Power 100 List in 2015. She is a long-standing member of Fight Colorectal Cancer's Medical Advisory Board, providing insight and guidance for 10 years.

"I started with colon cancer research when I was a resident," Mitchell said. "I was impressed by the fact that there were so many people with colon and rectal cancer and there was such a dismal prognosis. I committed myself then."

After years in the fight, she's encouraged by what she observes on the front lines.

"It's been very gratifying ... to see the amazing new drugs, new methodologies and new regimens that have afforded patients a better lifestyle, a longer life and in some cases a cure, at least a presumptive cure," she said. "It's been extremely gratifying to have patients undergo one treatment after another and yet have good outcomes and results."

A common thread in these breakthroughs has been patient participation in clinical trials.

"We do not have all the answers to colon and rectal cancer now," Mitchell said. "We've made tremendous strides in last 25 years and if we are going to continue that momentum it will be important to participate [in trials]."

Those who joined trials decades ago are, in part, responsible for today's successful treatments.

"Twenty-five years ago none of the newer drugs we have available were on the market," she said. "If those early patients had not participated in clinical trials, we would not have those drugs."

Since trials are so important, why is participation so low?



Dr. Edith Mitchell serves as the Director of the Center to Eliminate Cancer Disparities and Associate Director for Diversity Affairs at the Sidney Kimmel Cancer Center. She is the current president of the National Medical Association.

Mitchell described several reasons:

- Some patients don't want to participate.
- Some physicians don't encourage involvement.
- Some trials require travel and extra expenses.

"Probably the most frequent reason is that once the diagnosis of cancer is made the patient is ready to get their treatment started without carefully researching the opportunities for optimizing therapy," she said.

In addition, some demographic groups are underrepresented in trials. These include people living in poverty, those with limited education, African Americans, Hispanics and adults under age 40.

Decreasing these disparities is part of Mitchell's work as president of the National Medical Association, the nation's oldest professional society for African American physicians.

Mitchell shared that a key to getting more people from all demographics into trials is for patients to have a caregiver or loved one serve as an advocate and help them learn about available treatment options, including clinical trials.

The bottom line: **"It's very important for patients to participate in good clinical trials and work with their physicians and other providers who can bring forward the latest in cancer treatment, research and technology."**



WATCH Dr. Mitchell explain skin toxicity and offer tips to patients dealing with this side effect at: [FightCRC.org/SkinTox](https://fightcrc.org/SkinTox)



BLUEPRINT

Convening the Research Experts

In cancer research, one promising field is immuno-oncology (IO), also known as immunotherapy. Immunotherapy uses the body's own immune system (with the help from science) to fight cancer. It has been all the rage and received widespread media attention after President Jimmy Carter's successful treatments for his advanced melanoma.

In 2015 we saw a breakthrough in colorectal cancer (CRC) immunotherapy for some patients with tumors classified as "MSI-high." These cures were derived from over 60 years of scientific inquiry. Although promising, the breakthrough may only affect 5% of patients.

We wanted to know how immunotherapy could impact the other 95% of CRC patients. Thanks to a donation made in memory of our late board member Gordon Cole, we began an innovative partnership with Cancer Research Institute (CRI) to convene a meeting of the world's experts to address this issue. CRI is an organization that has broadly focused on cancer immunotherapy for over 65 years. Together, we made CRC immunotherapy a squeaky wheel.

We hosted a face-to-face summit where, often for the first time, global experts dialogued about the status of CRC immunotherapy research.

Following the Summit, the experts developed a blueprint for advancing immunotherapies for all forms of CRC. The blueprint was presented during the Town Hall of the 2016 American Association of Cancer Research (AACR) annual meeting.

The experts, the CRC Immunotherapy Workgroup, are now putting the blueprint's plans into motion to help evolve IO science as it relates to colorectal cancer.

At Fight CRC, we will:

- Continue initiating and convening an active dialogue amongst the experts.
- Directly fund research for the priorities identified in the blueprint.

SUMMIT PARTICIPANTS INCLUDED:

- **Dr. Dung T. Le, co-chair**
Johns Hopkins Sidney Kimmel Comprehensive Cancer Center
- **Dr. Al B. Benson III, co-chair**
Robert H. Lurie Comprehensive Cancer Center of Northwestern University
- **Dr. Emily Chan**
Vanderbilt University
- **Dr. Dustin Deming**
University of Wisconsin
- **Dr. Luis Diaz**
Johns Hopkins
- **Dr. Wolf Fridman**
INSERM
- **Dr. Franck Housseau**
Johns Hopkins
- **Dr. S. Peter Kang**
Merck
- **Dr. Smitha Krishnamurth**
Case Western University
- **Dr. Wells Messersmith**
University of Colorado
- **Dr. Cynthia L. Sears**
Johns Hopkins
- **Dr. Neil Segal**
Memorial Sloan Kettering
- **Dr. Arvin Yang**
Bristol Myers Squibb
- **Dr. Rebecca Moss**
Bristol Myers Squibb
- **Dr. Edward Cha**
Genentech
- **Dr. Tom Dubensky**
Aduro Biotech
- **Dr. Aimee Murphy**
Aduro Biotech
- **Andrea (Andi) Dwyer**
University of Colorado Fight CRC
- **Anjee Davis**
Fight CRC President
- **Dr. Jill O'Donnell-Tormey**
CRI President
- **Dr. Vanessa Lucy** | CRI
- **Dr. Arthur Brodsky** | CRI
- **Nancy Roach**
Fight CRC Founder
- **Dr. Michael Morse**
Duke University
- **Dr. Elizabeth Jaffee**
John Hopkins
- **Dr. Christopher Lieu**
University of Colorado
- **Dr. Stan Hamilton**
MD Anderson
- **Dr. Richard Goldberg**
Ohio State
- **Dr. Robert Binder**
University of Pittsburgh
- **Dr. Tom Marsilje**
Fight CRC Patient Advocate
- **Keavy McAbee** | Fight CRC

- Seek opportunities for outreach and inform our partners at the National Cancer Institute (NCI), the Department of Defense (DoD) and large philanthropic funders about the blueprint priorities.
- Advocate for policies to support the guidelines approved recommendations for immunotherapy.

What can YOU do?

- ▶ **TELL:** Let people know about this great project!
- ▶ **SUPPORT:** Donate to fund more research.
- ▶ **SIGN UP:** Stay informed.



To get real-time updates on colorectal cancer resources and information, join the "Fight CRC Patient Resource Group" on Facebook!



IN THE FIELD

From fundraisers to conferences to the research labs – check out where our team & advocates have been lately.



COLON CANCER AWARENESS POST A SELFIE WITH #STRONGARMSELFIE TO TWITTER OR INSTAGRAM AND CRC WILL GET \$1 PER POST OR LIKE
CAVS GAME



ANJEE WINS LAUREL AWARD FOR ADVOCACY



IO BLUEPRINT MEETING

NEW YORK CITY



DOUG ULMAN SPEAKS

WASHINGTON, D.C.
10th Annual Call-on Congress



ADVOCATES ATTEND HILL BRIEFING



WASHINGTON, D.C.

Advocates met with notable members of Congress including Speaker of the House Rep. Paul Ryan (WI)



"UNDER 50" PANEL

NASHVILLE



TIMES SQUARE



SHARING PATIENT RESOURCES

WASHINGTON, D.C.
Ruesch Center Symposium



NASDAQ BELL RINGING



RATS IN COLORADO



NO-SHAVE NOVEMBER DONATES \$378,650!



RAISING AWARENESS

One Million Strong Milwaukee

HOPE WITHIN REACH

We reached over 300 million people for Colorectal Cancer Awareness Month in **March 2016**. Here's how we did it, who we met and where we're headed next.

GOOD Impressions

96.2M+
#OMScollection
campaign impressions

90K+
website visits

115.6M+
PSA impressions

3K
watched #ScopeScope
(live colonoscopy from
Mayo Clinic)

629
watched the live stream

131
congressional
meetings

10K+
emails to Congress with
partner support

Fight For.... It was a common anthem this year during Colorectal Cancer Awareness Month. Survivors and loved ones came fighting for their families, policy makers for constituents and researchers for a cure. From Capitol Hill steps to patients' hospital beds, #StrongArmSelfie pictures flooded in to show support for the cause and the fighting strength of the community.

This year we saw amazing contributions to the **One Million Strong Collection** (see them at OMScollection.org). We had **PSAs in Times Square and running on television, including the CNN Airport News Network**. The 10th annual Call-on Congress hosted more advocates and celebrities than ever – something the **Washington Post** reported on. Stories associated with One Million Strong received widespread media and online attention through **USA Today, Fox Sports Ohio, Cure Magazine**, among others. The Showcase in Nashville educated and inspired an online and live audience to get involved and be a part of a change.

Colorectal Cancer Awareness Month is *technically* in March, but Fight CRC advocates and staff work year-round to keep voices heard and make a difference. It takes individuals using our patient resources and getting involved in advocacy, philanthropy, awareness and research efforts to truly make a lasting impact. No matter what month is showing on the calendar, we need you. Come join us. At Fight CRC, we fight for YOU.

Learn about how to get involved at:
FightCRC.org/DoSomething



I Fight For Survivors

PATSY. Although this stage IV fighter is no longer with us, her passion for education and the #StrongArmSelfie lives on. After her passing, Kansas constituents shared her story with lawmakers through an action alert. During her funeral, guests did a #StrongArmSelfie in her honor and since then, her son's baseball team players sewed patches featuring a "strong arm" onto their jerseys to keep her legacy alive.

LOUISE. Stage IV fighter Louise had done a lot of research and received over five years of treatment by the time she found *Your Guide in the Fight*. Once she downloaded it, she took it to her infusion center and oncologist's office to advise them on their follow-up treatment plans. She said, "The book gives a good balance of hope and honest information." (Get yours at FightCRC.org/Guide)

ANDREA. After hearing our staff member Michell Baker talk about losing her father to CRC and getting screened herself at the One Million Strong Milwaukee event, Andrea realized she needed to be screened too. In light of her own family history, she scheduled a screening appointment just days after hearing Michell's story.

JO BETH. For educators, few excuses provide a reason to miss school but for 5th grade teacher and stage III survivor Jo Beth, advocacy got a pass. After learning about the importance of engaging in policy as a Fight CRC ambassador, Jo Beth and her family missed a few days of school to attend Call-on Congress. It was more important than anything to be amongst advocates and use her voice for herself, her boys and the One Million Strong community on the Hill. (Join us next year! See page 13.)

Why do YOU fight?

Tell us at FightCRC.org/ShareYourStory



Fight CRC National Spokesman &
Country Music Artist
Craig Campbell
Lost his dad to CRC

© Photo by Evan Cantwell

Blessings In Disguise

At age 26, Shannon Davis and her husband, Rep. Rodney Davis, faced colorectal cancer. Below is the story she shared to a room full of advocates during the 10th annual Call-on Congress.

By Shannon Davis

It's been 17 years since I took my last treatment.

I was diagnosed and had my surgery in March, which is ironically Colorectal Cancer Awareness Month.

Maybe not the day I was diagnosed, but soon after, I saw how my diagnosis was a blessing in my life for a lot of reasons.

Before my diagnosis, I was 26 years old and working as a home care nurse. They called me the “beginning and the end” nurse – I took care of babies and hospice patients.

I noticed I wasn't feeling well and shared it with some friends at work. I thought something was wrong with my thyroid. So, I did my own blood work.

The doctor who ran my tests called me back and asked if I was still working, he wanted to talk to me. My tests showed I was extremely anemic with a very low hemoglobin. He was worried about me having a heart attack and wanted to set up a blood transfusion.

“RIGHT AWAY I KNEW IT WAS CANCER.”

My family has a long cancer background – I told my doctor that. He sat me down with my friend who's also a nurse and told me I was overreacting. For six months it was assumed I had a blood disorder and I got a transfusion. My husband teased me that I was just out of shape as an explanation for why I was tired and got winded when going up the stairs – something I'll never let him live down.

Six months after I first reported not feeling well, I finally got a colonoscopy and was diagnosed with stage II colon cancer. I had a resection and six months of chemotherapy. It was determined I have Lynch syndrome – a genetic disorder that puts me at a higher risk



Shannon Davis, stage II survivor and Rep. Rodney Davis (IL), her caregiver

© Photo by Brian Threlkeld



FightCRC.org



Toll-free Resource Line: (877) 427-2111



Facebook.com/FightCRC



Twitter.com/FightCRC

ABOUT LYNCH SYNDROME

LYNCH SYNDROME is one of the genetic disorders that elevates one’s risk of colorectal cancer. It’s estimated that 1 in 370 people have it; only 1.2% of them are aware. Recent immunotherapy research has shown promise for patients with tumors with “Microsatellite Instability” (MSI), which is common amongst Lynch patients.

Learn more about this research and Lynch syndrome at: FightCRC.org/Lynch

for colorectal cancer, among others. I’ve since had other surgeries and frequent tests to monitor me and help me avoid another occurrence.

Going through cancer was really hard, especially as a younger patient. I saw a lot of support out there for younger breast cancer patients, but nothing for me as a 26-year-old colon cancer patient. There wasn’t anyone out there for me to reach out to. But a lot has changed since then. It’s awesome to see all of the advocates at Fight Colorectal Cancer.

I have asked, “Why me?” “Why did this happen to me and why at this time?” I’ve concluded that it happened so I could be a better person. And because it happened, I’m able to see blessings in my life.

ONE – Rodney. I don’t know what it feels like to be a spouse of a cancer patient. He was there for me every single treatment. After surgery they had to hold him back from going into the recovery room to see me. He has been with me every step of the way.

TWO – I am a nurse. My cancer experience helps me take better care of my patients. I’m a better advocate for them and their family members. Hospice patients often feel like nobody understands but some of them who learned about my story felt like they could talk to me.

THREE – My kids. I wanted to have more kids after I was diagnosed. We had a 2-year-old, but I wanted her to have a sibling. During treatment I would pray that I could have more kids as long as I would be around to raise them. Well, we were fortunate and I did have more kids. In fact we had twins!

I try to take my diagnosis and journey through cancer and see blessings along the way. It’s a big opportunity to share my story and be part of a great celebration and cause.



WATCH: See us united on the Hill at Call-on Congress 2016
[YouTube.com/FightCRC](https://www.youtube.com/FightCRC)

COLORECTAL CANCER UNDER 50

Shannon is one of the faces of “early-onset colorectal cancer.” While colorectal cancer rates in the U.S. are decreasing, incidence among patients under age 50 is increasing. Fight Colorectal Cancer is working alongside researchers, clinicians, policy makers and survivors to understand why this phenomenon is occurring and how to prevent these cases.

▶ **Have You Been Impacted?**

Share your story with us AND get notified when it’s time to take advocacy action regarding this issue. FightCRC.org/SignUp



Save-the-date for our
2017 Call-on Congress:
March 13-15
CallonCongress.org

What does it mean to fund research?

At Fight Colorectal Cancer, we go beyond just providing financial support for research. Here's what we mean.

▶ **We provide grants to scientists.**

We started this through our Lisa Fund, a fund focused on late-stage research. We have funded over 6 grants to young scientists totaling over \$485,000.

▶ **We train research advocates.**

Our research advocacy training and support (RATS) program teaches patients, caregivers and family members how to work alongside scientists.

▶ **We push for better policies to support research in a big way.**

Our team works hard year-round to inform and convene policy makers, experts and coalitions – reminding them we need their help to find a cure. We are the squeaky wheel pushing for answers and asking for federal support.

We believe anyone with a passion for colorectal cancer can be involved in CRC research. This can mean participation in clinical trials, or involvement in the agenda, design and review process. It can also mean donations and funding – which are just as critically important.

We urge you to participate, engage, and support our efforts.

Get started at FightCRC.org/Research



RING LEADER: ACTOR LUKE PERRY

Luke Perry isn't just a 90's heartthrob and actor, he's also a colorectal cancer activist! For the second year in a row, Luke joined Fight CRC to raise awareness and money. He moderated a panel during the One Million Strong Showcase pushing us to find ways to raise awareness, better understand the disease and push people to talk about prevention. Luke's using his celebrity power to shine a light on colorectal cancer. To volunteer your time and talents, go to FightCRC.org/Volunteer



Thank you, Luke Perry!



PLAYBACK: Miss the Showcase? Watch the discussion at [YouTube.com/FightCRC](https://www.youtube.com/FightCRC)



SPOTLIGHT: Tyrone and the Kroger Bakery



After volunteering with us at the Cleveland Cavaliers game, Tyrone wanted to do more with Fight CRC. He went back to work at the Kroger bakery in Columbus, Ohio and organized a tear sheet fundraiser. This gave him a way to raise awareness by displaying the "I Fight For" tear sheets all around the store. It also raised money for the cause – Tyrone's customers and co-workers raised over \$600.

"It's going to take events like this and multiple conversations to conquer colorectal cancer. We are happy to be involved in the discussion and work with Fight CRC to help make a difference."
~ Tyrone Doss

To host your own tear sheet fundraiser or learn more, go to FightCRC.org/TearSheet



LIVING LEGACY



Fight Colorectal Cancer received donations in honor or memory of the individuals listed below from July 1 through December 31, 2015. Their living legacy, through these generous donations, keeps the fight alive – for all of us. Thank you.

IN HONOR OF:

- Wanda Addy
- Stuart Barnes
- Aaron Begger
- Karen Bloom
- Daniel Bloomgarden
- Dawn & Wendell Bratburd
- Mike Bridges
- Danielle Burgess
- Michael Butler
- Natalie Byrnes
- Bob & Marlene Ceragno
- Judith Clifford
- Constantine Contopoulos
- Debbie Contopoulos
- Keith Eisla
- Shawn Faller
- Randy Fansler
- Sherri Faulconbridge
- Mark Flak
- Larry Fleishman
- Tracy Foss
- Teresa Frey
- Dylan Gonda
- Brian Greenlaw
- Ben Harris
- Rose Hausmann
- Joey & Martha Hinson
- Tracy Holmes
- Anthony Honaker
- Michael & Candi Jacob
- Marcia James
- Scott Johnson
- Judge Nancy Katz
- Perri Koll
- Mark Krafick
- Andrea Kramer
- Claire Li & Mom
- Qingwen Li
- Colleen Mackowick
- Coach Hunt Magee
- Christopher Matyjasik
- Carmen Mccalmon
- Mary Megan Mooberry
- Matt Mikkelson
- Lewis Moore
- Tammy Moore
- Kathy Oliver
- Lisa Owens
- Patsy Petzold
- Emma and David Pick
- Puget Sound Gastroenterology Edmunds
- Gloria Pruzan
- Tanya Pyatokha
- Jim Quinlivan
- Michael Robertson
- John Rogers
- Darin Rubino
- Dana Rye
- Carolyn & Kenneth Rye
- Anne Schaar
- Alex Schaefer
- Robyn Schmid
- Pamela Seijo
- Dennis Sievert
- Andrew Stingis
- Todd Swygart
- Jaymi Tadeo
- Kim Taylor
- Derek Taylor & Dad
- Buneesa Terry
- Sean Twersky
- Sid Verma
- Peter Wayson
- Tawndra Webb
- Margaret Webber
- Chris Wheeler
- Tim Wright
- Erin & August Zajonc
- Jamie Zakalik
- Mario V. & Kieran H.
- Karen, Jamie and Lori
- The GAC Past & Current
- Fight CRC Staff



SPARKS OF STRENGTH:

Sparks of Strength is a community event that remembers those we've lost and honors fighters surviving colorectal cancer through a luminary ceremony. The event can be tailored to your community's interests and needs. To learn more, organize an event and see pictures from past events, go to

FightCRC.org/SparksOfStrength

IN MEMORY OF:

- Laura Acquisto
- Johanna Buck Appleman
- Mr. Aqui
- Joyce Aronson
- Steve Baker
- Melissa Bates
- Daniel Beber
- Don Blair
- Cindy Bloom
- Jordan Breeding
- Hector I. Caban
- Don Caldwell
- Cindy Causley-Disque
- Robert Chalmers
- Gail Chavez
- Leonard Cmiel
- Ida & Julius Cohen
- Gordon Cole
- Sandy Connolly
- Roxie Costanza
- Randall Cox
- Francisco Deguzman
- Carmelo Delgado
- Rosetta Demarco Ragusa
- Dean Dennis
- Josien Doornink
- Nancy Eastman
- Shirlean Edmonds
- LeAnn Edmonds-Horton
- William Elliott
- Michael Evans
- Alice Fay Farmer Barnette
- Frank Fava
- Nancy Howard Ferguson
- Papau Ferre
- Peter Fess
- Margaret Reed Finch
- Patricia Fleishman-Gooder
- Paul Gartman
- Andrzej Gawecki
- Emma Gaytan
- Andy Giusti
- Andy Gomez
- Jim Grace
- Richard Grottle
- Queah Habern
- Michael Halverson
- Shannon Hamilton
- Jack Hawthorne
- Neal Hechtkopf
- George A. Henderson
- James Huffman
- Robert Ipekjian
- Jack Jackson
- Grandma Jake
- Angela Jennings
- Ton Jurriens
- Harold Keck
- Joseph Kloc
- Charles Kramer
- Lloyd Landkamer
- Janie Langston
- Timothy Law
- Norm Lawry
- Sandra Lesh
- Stephen Lindenbaum
- Joyce Longfellow
- Fran Mann
- Jerry Matter
- Paula Mcivor
- Peter Mercieri
- Robert Michelson
- Susan Middleton
- Elizabeth Miller
- Nora Mont'ros
- Ed Moody
- Betty Mortensen
- Jason Moses
- Arlene Murphy
- Bobby Newton
- Deborah Nichols
- Christine Niemi
- Kevin O'Halla
- Janet Obert
- Amy Ostermeier
- Harkin Owen
- Edwin Owens
- Abby Panken
- Don Passarella
- Thelma Louise Payne
- Angela Pernatozzi
- Emma Petruzzi-King
- Eli Pick
- Michelle Pirc
- Carolyn Poepping
- David Polino
- Ronald D. Ramsey
- Les Renck
- Michael Rogers
- Chris Rosebrugh
- Robert Rosenfeld
- Donald Rowley
- Vincent Ruiz
- Kathleen Ryder
- Fred Schmidt
- Richard Schwartz
- Aren Shank
- Gregory Siler
- Elizabeth Snyder
- Erica Snyder's Mom
- August Stango
- Jan Starczyk
- Donna Stoddard
- John Sunderland
- Judith (Suey) Sutton
- Roman Szumnarski
- Shannon Thiel-Gospodarek
- Elias Vasquez
- Jerry & Bud Vieger
- Terry Vogel
- Tim Vose
- Diane Wade
- Ellen Waters-Thomas
- Robert Webster
- Tammy Lynn Williams Moore
- C. Vincent Wilson
- Francis Woods
- Patrick Yaklin
- Grover Yawn
- Lenny York
- Wendy Zerby Truitt

**GET YOUR LOVED ONE FEATURED
IN THE NEXT BEYOND BLUE!**



Visit Give.FightCRC.org
or call (703) 548-1225
to make a donation.



**FIGHT
COLORECTAL
CANCER**

get behind a cure.

BEYOND BLUE

This issue of Beyond Blue is reaching thousands of patients, caregivers and loved ones facing colorectal cancer thanks to the generous support of these sponsors:

AMGEN

Genentech
A Member of the Roche Group

Lilly

To learn how to sponsor and support Beyond Blue, go to FightCRC.org/FundtheFight

- ♥ **DO YOU LOVE BEYOND BLUE?** Become a distributor and share it with your local cancer center. Sign up at FightCRC.org/SignUp
- 💬 **TALK TO US!** Send us your story and tell us why you LOVE this magazine at FightCRC.org/ShareYourStory