

# BEYOND BLUE

**FIGHT COLORECTAL CANCER**

VOLUME 18 • ISSUE 2

RELATIONSHIPS

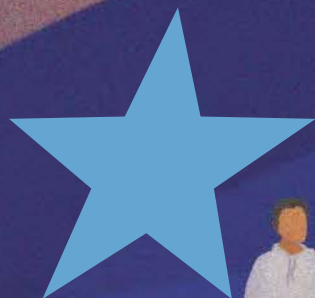
SETTING *Boundaries*  
+ MOVING ON

**report  
cards**

UNDERSTAND YOUR  
TESTS *and* SCANS

SCANXIETY

TIPS FOR FACING  
*the UNKNOWN*



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



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

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



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### **Disclaimer**

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## Word Search

### Put to the Test

O	C	A	C	H	A	M	P	I	O	N	T	E	I
C	H	A	L	L	E	N	G	E	P	D	E	N	S
B	R	N	N	M	R	F	T	S	C	A	N	S	E
S	S	O	O	I	E	N	O	G	N	G	C	O	E
E	T	O	R	I	H	M	E	N	N	H	A	H	K
I	R	S	R	A	T	N	E	O	E	C	N	R	R
M	O	G	R	S	E	C	I	I	P	S	X	R	O
A	P	W	R	T	M	C	E	S	E	L	I	O	W
G	E	M	I	N	S	N	I	N	R	H	E	T	D
I	R	C	N	C	T	N	O	E	N	M	T	I	O
N	S	E	S	E	S	N	G	T	O	O	Y	E	O
G	E	R	E	M	I	S	S	I	O	N	C	I	L
C	O	M	M	U	N	I	C	A	T	I	O	N	B
O	M	R	I	C	T	R	O	P	P	U	S	N	O

## WORD BANK

Anxiety  
Bloodwork  
Challenge  
Champion  
Communication  
Connection  
Genetics  
Grief  
Imaging  
MRI  
NED  
Reports  
Remission  
Scans  
Support  
Tension

## Jokes

### Why did the toilet roll down the hill?

*To get to the bottom!*

### What did the poo say to the fart?

*"You blow me away!"*

### What do you do if you find a bear on your toilet?

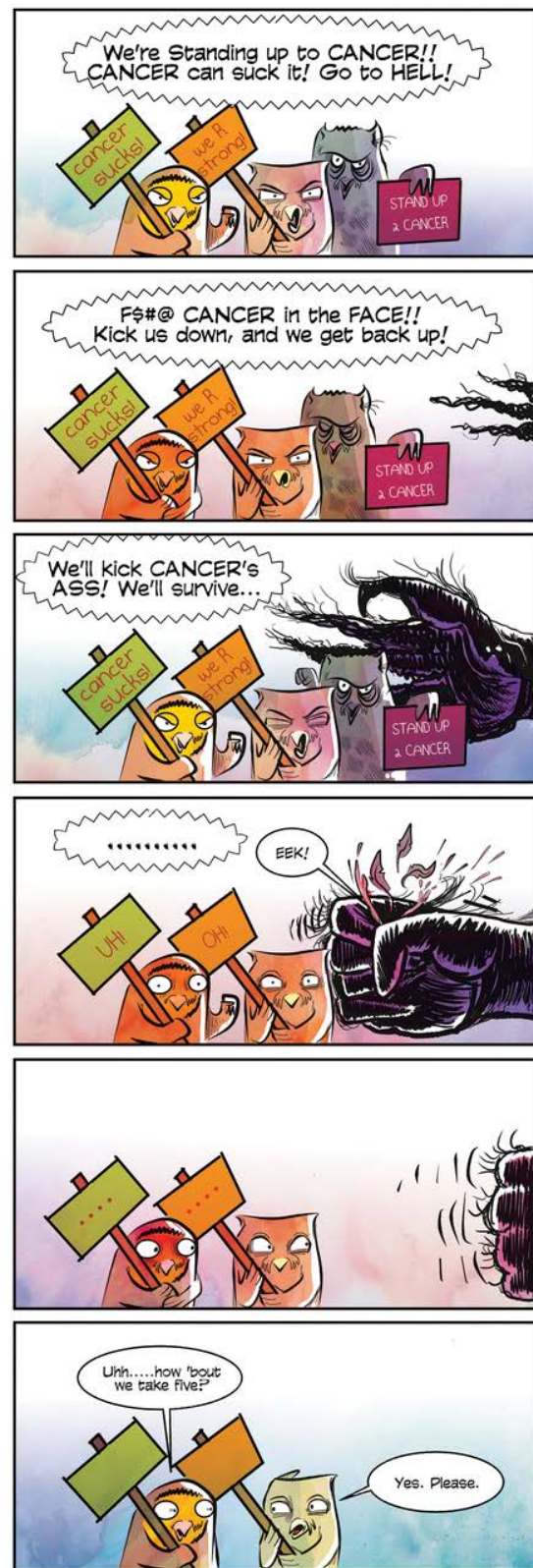
*Let it finish!*

Jokes originally posted on beano.com.

**SUBMIT A JOKE!**

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

## Comic



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

Cancer Owl is a creation of stage II survivor Matthew Paul Mewhorter. Visit his work at [cancerowl.com](http://cancerowl.com).

Comic reprinted with permission.





**FOLLOW  
ANJEE!**

@anjeedavis



## Embracing Our Tests

Life often presents us with trials that challenge our very core, pushing us to our limits.

However, it is during these trying times that we discover the remarkable strength and resilience that reside within us. Stories of individuals who have faced tests head-on—emerging stronger, wiser, and more determined than ever—inspire us. Seeing the indomitable courage and unwavering faith in others can guide us through our darkest moments, reminding us that even in the face of adversity, we possess the power to grow, heal, and thrive.

In this issue of *Beyond Blue*, our contributing experts, survivors, and caregivers provide valuable insights and practical strategies to navigate physical, mental, and emotional well-being. We explore topics like the importance of setting boundaries in our relationships and ways to find mindfulness when facing scans. We also educate on the plethora of tests available to patients, like ctDNA testing and genomic profiling. New testing technologies are leading to breakthroughs that not only improve early detection of colorectal cancer, but are also helping our health care teams tailor treatment plans for better outcomes and enhanced quality of life.

**Our extraordinary team that curates the stories in *Beyond Blue*, and all of the patients and caregivers who contribute, are committed to creating a magazine that inspires, uplifts, and offers a sanctuary for growth and reflection. Their passion shines through every page.**

At Fight CRC, we are committed to fostering a compassionate and supportive community because we understand that when you're put to the test, you need a network that empathizes with your experiences. We believe in the power of collective healing and the strength that comes from sharing our stories. In this spirit, we invite you to join us on this transformative journey as we navigate the trials and triumphs of the human experience together.

Thank you for being a part of our community and for your continued support in our mission. Together, let us embrace our tests: finding healing, strength, faith, hope, and empowerment in the process.

**YOURS IN THE FIGHT,**

**Anjee Davis, MPPA  
FIGHT CRC PRESIDENT**

**\* GROW HEAL THRIVE**



Thoughts about **BEYOND BLUE**



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**Scan to read  
and subscribe.**



**TRISHA MOUZON**

*Stage III Survivor  
South Carolina*

"I love the showcase of resilience and tenacity that all survivors share in their individual stories in *Beyond Blue*!"

**We want to hear  
from you!**

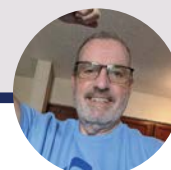
What do you think about this issue? Send your feedback to [danielle@fightcrc.org](mailto:danielle@fightcrc.org).



**PAULA CHAMBERS**

*Stage I Survivor, Texas*

"One of the things I love most about reading *Beyond Blue* is discovering the latest research in colorectal cancer. However, what truly makes being a research champ special for me is the opportunity to interact with my favorite GI doctor and his exceptional team. They're passionate about providing Fight CRC resources to their patients, and the office manager mentioned that each edition offers something valuable for visitors in their waiting areas."



**TIM MCDONALD**

*Stage IV Survivor, Florida*

"*Beyond Blue* answers the questions we were wanting to ask. It introduces us to real people who are going through what we are going through and is often the connector for what becomes long-lasting relationships between survivors."



**Tami Pangelina**

*Caregiver,  
California*

"Dropped off literature today! The receptionist's niece was just diagnosed with stage III rectal cancer so

my timing was on point! She was so thankful for the resources and learning about Fight CRC."



**Pam Allen**

*Stage III  
Survivor,  
Georgia*

"I placed the surgery brochures in the surgeons' waiting room of the Lake Russell Specialty

Building, and within a few weeks I was asked to bring more. Thanks, guys, for putting together this powerful, well-informed brochure. This has helped so many to prepare for surgery, from asking questions, packing, and what to expect afterward. The work never stops!"



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

You'll receive a **FREE** box of 10 magazines and other resources each time we release an issue of *Beyond Blue*.

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

## Speaking Up

A few months ago, I returned to a place I had not been in 14 years: the operating room. I now have a permanent ileostomy, and I am a three-time colorectal cancer survivor.

We caught my latest cancer very early, and thankfully, surgery was all I needed. But there's nothing like the smell of hospital hallways and the taste of orange JELL-O® to bring back a flood of memories. In the midst of emotionally coping with the news, I was also logging on to check for my CT scan results and lab work, refreshing the app by the minute at times. I wanted to know the latest about my health, and I was determined to read the reports myself.

Being back in that hospital bed was a visceral reminder of the challenges we face as patients and caregivers. Colorectal cancer tests us in every way: mentally, emotionally, physically, and spiritually. And while I'm not going to sugarcoat the cancer journey—it's stinking hard—I am going to share that being an advocate has helped me get through it.

The Fight CRC family came through for me with encouragement, thoughts, prayers, and relevant advice and resources. My local friends and family carried me through yet another diagnosis. After a decade of serving in the colorectal cancer community, the knowledge and practice of advocating for myself and others came in handy. I had to speak up, and I sometimes stood up, to doctors and nurses regarding my care. This got me out of the hospital and onto a road to recovery much quicker.

It's important for us to know our rights, get educated, and stand up for ourselves when we're put to the test. Nothing about cancer is easy, but as we face our challenges head-on, it truly makes us stronger. We're not helpless. We're not alone. So let's keep going and not quit. We are, after all, relentless champions of hope.

### FOLLOW DANIELLE!

@DanielleisB



### ABOUT THE EDITOR

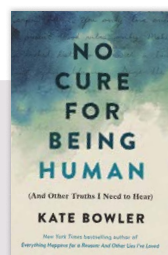
Danielle Ripley-Burgess is a 20+ year colorectal cancer survivor who was first diagnosed at age 17. She has Lynch syndrome. Danielle is the author of "Blush: How I Barely Survived 17", and she serves as Fight CRC's Chief Storyteller.

### STAY STRONG,

*Danielle Ripley-Burgess*

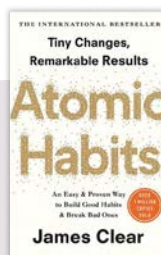
**Danielle Ripley-Burgess**

**CHIEF STORYTELLER & EDITOR-IN-CHIEF**



### NO CURE FOR BEING HUMAN

*By Kate Bowler*



### ATOMIC HABITS

*By James Clear*



### FULL CIRCLE

*By Jessica Catlin*



### THE BEAUTY OF WHAT REMAINS

*By Steve Leder*

## Book SHELF

**RECOMMENDED  
READS FROM THE  
Fight CRC Team**

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

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





# FIGHT CRC *and* THE COLON CLUB MERGE

Fight CRC and The Colon Club, a nonprofit that has been raising awareness of colorectal cancer in young adults in "out-of-the-box" ways since the early 2000s, have combined forces and are now tackling colorectal cancer as one organization!

After decades of working together as partners, the two groups have come together to increase impact and expand reach into the early-onset colorectal cancer community. The Colon Club, known for projects like the Colossal Colon, *The Colondar*, and *On the Rise* magazine, will bring its youthful energy and enthusiasm for reaching young adult patients to Fight CRC's patient education, research, and advocacy efforts. Read more about The Colon Club and what's next on page 34.



**READ MORE**

Scan the QR code to read more about the merger.

## FIND YOUR AMANDA

Molly McMaster (pictured right) connected with another young survivor, Amanda Sherwood Roberts (pictured left), and it changed her life and inspired her to create *The Colossal Colon* and later, co-found The Colon Club with Amanda's cousin, Hannah. The Colon Club exists so other young patients can "find their Amanda" and not feel so alone.



"We are proud that The Colon Club has entrusted Fight CRC with the responsibility of carrying forward their mission to raise awareness for early-age onset colorectal cancer. Fight CRC will continue the work of The Colon Club by providing a safe place for young survivors to meet and share stories."

**Anjee Davis**  
FIGHT CRC PRESIDENT



"I was fortunate enough to be able to step away from The Colon Club for a few years and when I came back to the table, it was incredible to see the changes: All because more people were allowed to add ideas. Fight CRC has been a large part of that because our missions and the people just seem to mesh. I'm beyond excited to see what's going to happen as more passion and experience are added to the mix."

**Molly McMaster Morgoslepov**  
THE COLON CLUB CO-FOUNDER

**We could  
not be ignored.**



**Advocates sent almost 1,200 action alerts, as well as countless tweets and posts on social media, demanding that UnitedHealthcare not implement a prior authorization program for GI procedures, and the outcry could not be ignored.**

On June 1, the day the prior authorization program was supposed to take effect, UnitedHealthcare announced they will delay the implementation of the program. While we celebrate the fact our relentless efforts paused the terrible policy, it's not over yet. We must keep pushing and keep them accountable, and we plan to continue pressuring UnitedHealthcare to do the right thing.



**ACT NOW**

Use your voice for change, scan to take action now!

## **First FDA-approved Treatment for HER2-positive Metastatic Colorectal Cancer**

The Food and Drug Administration (FDA) has granted accelerated approval for a combination therapy for patients who qualify, with one criteria being HER2-positive metastatic colorectal cancer. HER2-positive is a biomarker initially discovered in breast cancer but also present in about 3% to 5% of colorectal cancer cases.



**READ MORE**

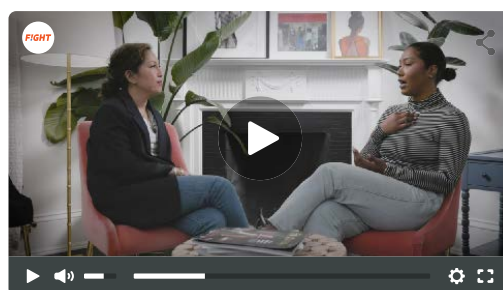
Scan the QR code to read more about this exciting new treatment option.



## **FDA RELAXES GUIDELINES FOR BLOOD DONATIONS**

In May 2023, the FDA relaxed their blood donation guidelines for gay and bisexual men. As reported by AP, "Gay and bisexual men in monogamous relationships can donate blood in the U.S. without abstaining from sex." Donating blood isn't only philanthropic, it can signal if someone is anemic.

**Anemia can be an early warning sign of colorectal cancer, and the ability to donate blood has caught anemia, which was being caused by early-stage disease, in many patients.**



**"IF WE HAD KNOWN..."**

**Last March, Simone Ledward Boseman captivated a White House audience as she shared about losing her husband, Chadwick Boseman, to colorectal cancer.**

She sat down with Fight CRC President Anjee Davis the day following to explain why she spoke out, and why health equity is so important.



**WATCH**

Watch Simone and Anjee's talk.



# AM I REALLY NO EVIDENCE (NED) of DISEASE?

An illustration of a person with dark skin, wearing an orange shirt and blue pants, running along a large, stylized DNA double helix. The helix is colored in shades of orange, blue, and white. The person is in a dynamic pose, leaning forward with arms outstretched, as if running or jumping. The background is a solid purple color.

**Surgery's over. You've been on treatment for months. So far, so good, you're responding—you think.**

You hope. The labs and CT scan show nothing worrisome. You get told you have no evidence of disease (NED), but are you really disease-free? Is there any cancer in your body? It's a question patients ask every day, and it's why many patients are turning to ctDNA tests.

## WHAT IS ctDNA?

ctDNA refers to circulating tumor DNA. Circulating refers to presence of the marker (in this case tumor DNA) in the bloodstream. In testing done in patients with colorectal cancer, the finding of ctDNA can be an important one. Traditionally, blood tests and imaging tests are used to determine if a treatment is working or if a patient is cancer-free. To be seen on imaging tests, tumors must reach a certain size (often about half an inch in diameter) to be detected, and not all colorectal cancers make biomarkers such as CEA that can be monitored using blood tests. But now, new technology has been developed to measure ctDNA. The discovery of tumor DNA in the blood signals the presence of residual disease and can detect the presence of cancer cells before other tests can do that.

Cancer cells shed DNA into the bloodstream at very low levels, and their detection is often termed minimal residual disease (MRD), acknowledging that this technique can find disease that is too small to be detected by other methods.

## WHAT CAN ctDNA TELL ME?

ctDNA is considered a biomarker that is both prognostic (gives information on how well a patient will do) and possibly even predictive (gives information on the likelihood of responding to or being resistant to specific treatments). These tests can detect MRD earlier than other studies, and they predict the likelihood of finding cancer on imaging tests in the future.

It's a very sensitive and specific way to discover early recurrence, and it can also show how you may or may not respond to treatment and what kinds of treatment you may need. ctDNA has been used for molecular profiling on biomarkers as an alternative to using tumor tissue, making biopsies unnecessary. It has many uses, and they're continuing to evolve.

## HOW DO I GET A ctDNA TEST?

Oncologists order and arrange to send ctDNA tests to specialized laboratories. They use a blood sample. Medical teams are using ctDNA tests in a variety of ways, but most patients know about their value for the MRD monitoring.

Signatera™, Colvera™, and Guardant Reveal™ are some of the most commonly known ctDNA tests that have been FDA approved and are offered by commercial laboratories used by patients.

*It's important to remember that these tests are not recommended for all patients, and insurance may or may not cover them.*

Patients have ctDNA testing performed repeatedly at intervals based on individual treatment plans, so work closely with your doctor. Ask about them if:

- You have stage II, III, or IV colorectal cancer.
- You've recently had surgery, and you're evaluating if you need chemotherapy to lower the risk your cancer will return, and/or if you want to know if any cancer cells remain.
- You're receiving treatment for colorectal cancer, and you want to know if it's working.
- You've completed treatment, and you want to closely monitor for any recurrence.

Medical review by Richard M. Goldberg, MD



## TERMS

### *to Know*

#### **Circulating tumor DNA (ctDNA)**

DNA from cancerous cells and tumors that's found in the bloodstream.

#### **Minimal residual disease (MRD)**

The presence of ctDNA in the body measured through blood tests.

#### **Prognostic biomarker**

A substance that can be measured in the blood or using biopsy material that can identify how well or poorly a patient may do based on the experience of prior patients.

#### **Predictive biomarker**

A substance that can be measured in the blood or using biopsy material to determine if a patient's tumors are likely to respond or be resistant to specific treatments based on the experience of prior patients.

#### **NED**

No evidence of disease.



### Jack's Experience

*I asked my former oncologist about a ctDNA test, and he said no.*

The new oncologist suggested it before I could ask. Now, we test every six months. My insurance recently denied the test, so I've had to talk to them and advocate for myself to get the test done. The ctDNA test backed up what my scans say, and both read NED. With science growing so fast, I think this is a better way to show if cancer may be active, and it may possibly lead to fewer scans, which means less dye and radiation.

#### **JACK BIRREN**

*Stage III Survivor • Wisconsin*



### Chris' Experience

*I believe MD Anderson uses Signatera on most CRC patients. They suggested it and ordered it.*

I get the tests every three months; I do a blood draw locally. My first and second Signatera tests arrived before my scans, and my scans backed up what my Signatera test said. It's always stressful waiting for any results, but as mine has remained zero so far, it does give me an enormous amount of peace of mind. The Signatera tests actually drove some of my post-surgery treatment plan. Because after surgery, I received a negative Signatera test, they removed oxaliplatin from my last two (of five) post-surgery chemo sessions.

#### **CHRISTINE BRONSTEIN**

*Stage III Survivor • Hawaii*



### Yvette's Experience

*I started Signatera when it was relatively new in 2019, and I had to go around my small cancer center's system and directly to Signatera.*

My small cancer center did not know what to do with it. I was actually discouraged from using it at first because they thought there wasn't enough evidence behind it. My center also had a hard time working with their system. I think Signatera's still not something they trust over CEA. I currently get a Signatera test every three months because I am stage IV, and it usually coincides with bloodwork for my CEA. We have found that the two tests work well together, and they alert me early when something is brewing. At one point, the ctDNA test indicated cancer, which resulted in a PET scan that showed a very tiny glowing cancer in scar tissue, which led to my last lung resection. The regular CT did not show that. Without the test, it would have grown while I was thinking I was NED. I am currently technically NED according to the scans. My Signatera is now showing positive for cancer, and it has since the lung resection. It trends up and down, but it's not in the trending area where it was showing a solid tumor. We are watching and waiting. There have been times when I wish I didn't do the test so I could "blissfully" live by the CT scan results alone. But I don't roll that way, and I 100% believe knowledge is power, and there is no such thing as too many tools in your toolbox.

#### **YVETTE PERRY**

*Stage IV Survivor • Oregon*



# REPORT *cards*





**They're one of the first things you need when you're diagnosed with colorectal cancer, and something that will stay with you for the rest of your life: tests.**

Lab tests. Biopsy tests. Genetic tests. Imaging tests. Surveillance tests.

They can throw you back to school days, wondering if you passed or failed, and what your future holds. If only medical reports were as easy to read as A's, B's, and F's.

While testing is something all patients face, few actually understand what's going on. How do you read a report? Who gets the report? When will the test be repeated? What do the acronyms mean? There are often more questions than answers when it comes to testing and results. But Fight CRC believes it shouldn't take a medical degree to understand.

As you're put to the test of colorectal cancer, let's eliminate some confusion when it comes to your testing results. Here are some of the most popular reports patients receive, and what each one says about you.



### Colonoscopy Report

For most colorectal cancer patients, the long road of testing begins after a colonoscopy. If your GI specialist found any polyps or masses during the procedure, a biopsy was most likely performed. A biopsy is when the polyp(s) or a portion of a mass was removed and sent to a pathologist. Your GI specialist should give you a colonoscopy report that explains what was found and any required follow-ups.

#### Typically includes:

- **Indications:** What led you to get the colonoscopy (signs, symptoms, age, etc.).
- **Impressions:** What was found during the procedure, oftentimes photos are included.

- **Recommendations:** Instructions on resuming or starting diet, medications, and activity; emergency contact numbers; follow-up conversations to have with the doctor; and when to repeat the procedure. Should also indicate if a biopsy was taken and if pathology results are to come.

*Who gets the report:* You. Immediately following your colonoscopy.

*Your next steps:* Adhere to the doctor's instructions for follow-up steps.

*When repeated:* Depends on the findings, and if you have a hereditary syndrome that predisposes you to a higher risk of developing polyps or tumors.



### Pathology Report

Any time tissue is removed from your body—from a colon polyp to a piece of a tumor—it is sent to a pathologist for careful review under a microscope. Pathology reports on colonoscopy specimens usually reveal the type of polyp and determine if it was precancerous or cancerous.

There are different kinds of colon polyps with different chances of developing into cancer if they are not removed, and the report will generally specify the type or types of polyps found.

Pathology reports after surgery that are done to remove a cancer and a portion of the colon or rectum, or those done after tumor biopsies, may share more information about if a tumor is cancerous, the size of the tumor, the tumor grade, and if it has spread to other organs.

#### Typically includes:

- Size of the specimen(s) and the location(s) removed from
- Description of the specimen(s) evaluated
- Diagnosis (also called histologic type)

*Continues to page 14*



Continued from page 13

## Common Polyp Findings

• **Hyperplastic and inflammatory polyps.** Usually benign and rarely turn into cancer.

• **Adenomas/adenomatous.**

Precancerous, may develop into cancer. Larger polyps are more likely to become cancerous, and polyps larger than 1 inch may already be cancerous.

- **Pedunculated.** Has a stalk and appears mushroom-like.
- **Sessile.** Flat, broad, and more likely to return.
- **Tubular.** Growth pattern of most small adenomas, a rounded shape.
- **Villous.** Growth pattern of many larger adenomas, a ruffled shape. Polyps are usually larger and more advanced.
- **Tubulovillous.** Growth pattern has both tubular and villous characteristics.
- **Sessile serrated and traditional serrated.** Look like a saw-tooth under the microscope and need to be removed.
- **Dysplasia.** Precancerous changes in the cells observed. Usually labeled as mild/moderate/severe, with severe being called high-grade. The higher the grade, the more likely it is that dysplasia will evolve to become cancer.
- **Adenocarcinoma.** Cancer/malignancy.

## Cancer Grades

A pathology report may reveal a histologic grade if your biopsy is cancerous. This grade indicates how quickly the cancer is expected to grow and spread.

**GX:** Grade cannot be determined.

**G1:** Cancer cells look similar to healthy cells. Called well differentiated or low grade.

**G2:** Cancer cells are somewhat different from healthy cells. Called moderately differentiated or intermediate grade.

**G3:** Cancer cells barely look like healthy cells. Called poorly differentiated or high grade.

**G4:** cancer cells are very abnormal looking. Highest grade and typically grow and spread faster than lower grade tumors. Also called undifferentiated or high grade.

## Stage Classification

Cancer grades are different from cancer stages, because grades are based on what the cells look like under a microscope and not where the cells have gone, which is how staging is determined. Before surgery, most staging is a clinical stage, determined by the colonoscopy, biopsy, labs, and imaging. After surgery, it's a pathologic stage, determined by all the above plus the colorectal specimen including lymph node status and invasion into adjacent organs. This gives a clearer picture of the stage of the cancer.

Your pathology report may tell you the TNM classification of your biopsy. This is used to stage your cancer. Your tumor will be given a score in each of these areas, and the score will determine your stage of cancer:

- **T (tumor):** How far the tumor has grown into or through the colon or rectum wall. (scored from 0–4)
- **N (node):** Whether any lymph nodes near the original tumor have cancer in them (scored from 0–3)

- **M (metastasis):** Whether cancer has spread to areas or organs outside the colon (scored from 0 to M1, M1a and M1b)

*Based on your TNM score, you will receive a stage 0, stage I, stage II, stage III, or stage IV diagnosis. Sometimes a, b, and c are added to your cancer stage to further subclassify the stage of the tumor as well, which is also determined by the TNM score.*

## Immunohistochemistry

Most colorectal cancers form from glands in the inner wall of the colon or rectum that make mucus. These tumors are called adenocarcinomas. Once an adenocarcinoma or any tumor is sent to pathology, immunohistochemistry (IHC) should be performed. This is a test that looks for the presence or absence of certain proteins in the tumor to determine if you could have a hereditary form of cancer. The proteins the IHC looks for are considered mismatch repair proteins (MMR), and they include: MLH1, PMS2, MSH2, and MSH6. Depending on if any of these proteins are present or absent in your pathology report, you may be referred to meet with a genetic counselor.

**Who gets the report:** The doctor who collected and sent the specimen, usually your GI specialist and/or surgeon. If your primary care doctor ordered the colonoscopy, they will also likely receive the report.

**Your next steps:** It can take 10–14 days for your pathology report to come in. Follow up with your doctor's office if they haven't contacted you about your results. Your report will dictate your next steps.

**When repeated:** Each time you have polyps removed during a colonoscopy and/or each time you have surgery or a biopsy performed.





## Lab Work

Blood tests are not unique to cancer patients, but they're critical because they can indicate things like how your body is handling treatment, whether you have vitamin/nutrient deficiencies, and some, called tumor markers, may indicate if your body contains more or less disease. These are the blood tests you'll be sent for routinely both during cancer treatment and beyond the time of treatment during follow-up care.

### **Complete blood count (CBC)**

Looks for numbers of white blood cells, red blood cells, and platelets.

### **Comprehensive metabolic panel (CMP)**

Looks for metabolites, electrolytes, and proteins.

### **Carcinoembryonic antigen (CEA)**

A protein found in the blood of some, but not all, people with colorectal cancer, and it's a tumor marker. For some people, the level of CEA in the blood is higher if they have more colorectal cancer cells in their bodies than what is considered typical. It can also be an indicator that the cancer is spreading to other organs if the CEA is rising over time, or that tumors are responding to treatment if the CEA is falling over time.

*If a doctor is suspecting other tumors, they may add liver function tests and other panels like CA 19-9, CA 125, and AFP.*

*Who gets the report:* The doctor who ordered your labs (often a primary care physician and/or oncologist) will receive the lab report, but you can request a paper copy. If your health system offers an online patient portal, your lab results are often stored there as well, and you can access them at any time.

*Your next steps:* Your health care providers will let you know if your numbers are normal and if not, what to do. Sometimes you'll be sent for more lab tests, imaging tests, or be directed to take certain medications and/or supplements depending on your lab results. If you're on treatment, your lab results may indicate its effect on your body and extra care you need.

*When repeated:* If you're in the hospital, blood is often taken every day. If you're receiving chemotherapy or targeted therapy, a lab draw is often required before each infusion. In follow-up care, labs are usually drawn around the time of each appointment.



## CT Scan Report

Every colorectal cancer patient will be sent for imaging at some point, and oftentimes at multiple points. Scans are helpful tools in helping your doctors see what is happening inside your body's organs. The CT scan (also called CAT scan) is the most common scan you'll be requested to get. A CT of the chest, abdomen, and pelvis can show where colorectal cancer is in your body. Doctors use this report to see if cancer has spread beyond the colon and if so, where and how far. Sometimes tumors are too small to be seen on scans, and tests may need to be repeated at intervals to find small masses.

CT scans can be done with and without contrast. Contrast refers to a drug or substance that can be taken by IV and/or orally, and it's dye that highlights tissues differently and can make abnormal findings easier to see. When you are going to receive oral or IV contrast, you are usually required to fast before the procedure, and it's typically a solution that you are asked to drink and/or it is injected into your veins.

### **Typically includes:**

- **Examination:** What the CT scan evaluated and if you did/didn't have contrast.
- **History and comparison:** If you have previous scans they're comparing it to.
- **Findings:** This will typically list out the organs/areas they see in the scan and how they appear. Not all findings reported on a CT scan are abnormal or related to cancer. For example: The radiologist may note if there are signs of arthritis in your bones or of liquid-filled sacs or cysts that may not be signs of illness.

*Continues to page 16*

# PRO TIPS

## ● GET THE APP

**Apps like MyChart, MyHealthOne, and others offered by hospitals and health systems can be great ways for you to get your reports and communicate with your doctors.**

Most hospitals now offer these tools for patients. If they haven't notified you about these options yet, request them!

## ● ADD ALL YOUR DOCTORS

**Adding all your doctors to reports saves both time and hassle.**

If you're checking in for any type of procedure, even a lab draw, you can ask for your reports to be sent to every doctor on your medical team. Include doctors both in the hospital network and outside of the hospital network.

# PRO TIPS

## ● OWN YOUR RECORDS

### **Remember: YOU own your medical records and reports.**

You have a right to ask for a printed copy of any report. You also have a right to request the images and/or film from your imaging tests.

## ● CLARIFY

### **Conversations involving your test results can be confusing, especially when it feels like you're learning a new language.**

Most patients do not have the scientific background that makes understanding the information quick and easy. Clarify what you're hearing with your health care team. Write down the details they share, and make notes on your handouts. Don't be embarrassed to ask questions.

*Continued from page 15*

- **Impression:** A summary of the findings and the most important findings, in the radiologist's opinion.

*Who gets the report:* The doctor who ordered your CT scan will get a detailed, written report. This report will live in your chart, but you can request a paper copy. You can also request a copy of the images and/or the film from radiology, but you need to give advance notice. If you have an online patient portal, your written imaging reports may also show up in there.

*Your next steps:* It's tempting to read your report on your own if you can access it. But make sure to talk to your doctor about what each finding means and decide together on next steps.

*When repeated:* Your doctor will determine when your CT scan needs to be repeated based on your treatment plan. Typically patients on active treatment are re-scanned every three or six months and follow-up care involves yearly scans up to five or more years.



### **Tumor Testing Reports A.K.A. Biomarker Reports**

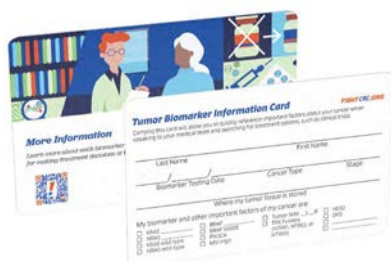
Because not all colorectal cancers are the same, knowing what biomarkers are in your tumor can provide valuable insights. Some biomarkers tell what kind of cancer you have; others tell if your tumor may respond well or poorly to certain treatments. Biomarkers can give clues about how your tumor may behave in the future, about dosing decisions, and also whether cancer is still circulating in your body once treatment ends. Ideally, your tumor will be tested for biomarkers as soon as it's

biopsied. In the event you've already had surgery and/or your doctor didn't request biomarker testing, ask your doctor where your tumor is stored. In nearly all cases, pieces of your tumor are stored in a tissue bank. You can still request biomarker testing to be performed on this tissue. Often biomarkers in a tumor can evolve over time, and sometimes these tests are repeated on new biopsy samples as patients receive treatments or develop new signs of disease.

Biomarker reports may vary. Sometimes the pathology report will indicate biomarkers, but not always. Specific reports for biomarker testing typically include:

- **Genomic findings:** Which biomarkers your tumor does/doesn't have.
- **Therapies:** Which FDA-approved therapies may work or are unlikely to work for you.
- **Other alterations and biomarkers identified:** Other markers found in your tumor.
- **Variant details:** Your report may also show the DNA sequencing of mutations or abnormal sections of your tumor's DNA (called somatic mutations) or your own DNA (called germline mutations). Sometimes these variants are inherited, and sometimes they are acquired rather than inherited.

Biomarker reports often contain hard-to-understand scientific language, but you can arrange to walk through them with your doctor, and don't be afraid to ask questions.



### **My Biomarker Passport**

Keep track of your biomarkers!

Our Biomarkers Brochure comes with a Biomarker Passport that helps you keep track of your biomarkers and other important factors of your tumor that affect your cancer care. Request a free copy at [FightCRC.org/Biomarkers](http://FightCRC.org/Biomarkers).



## Common Biomarkers

### **DNA Mismatch Repair (MMR)**

This was likely performed when your tumor was first biopsied.

**Microsatellite status** Results will show MSS/MSI-High/MSI-Low.

**RAS genes** (KRAS or NRAS) Wild-type means negative; positive means there's a mutation on that gene that's causing the cancer.

### **BRAF/BRAF V600E**

### **PIK3CA**

### **HER2**

### **TRK Fusions** NTRK1, NTRK2, or NTRK3

To learn more about biomarker testing and what each biomarker means, visit [FightCRC.org/Biomarkers](http://FightCRC.org/Biomarkers).

It's important to remember that biomarker testing is performed on cancer cells, and it's NOT the same as genetic testing performed on healthy cells that have not become cancerous.

*Who gets the report:* Your surgeon and/or oncologist.

*Your next steps:* Ask your doctor to review your biomarkers and make treatment decisions based on the results.

*When repeated:* Typically not repeated unless a second tumor is removed.



## Genetic Testing Reports

Genetic testing will help you and your medical team determine if you have an inherited cancer risk. All colorectal cancer tumors should have MMR testing performed on them once biopsied, and if the pathology indicates the tumor may be genetically linked to an inherited condition that may predispose you and your family members to develop cancer, you'll be referred to a genetic counselor.

You and your family members may be candidates for genetic counseling, even if MMR testing is normal, if there's a strong family history of colorectal cancer; if you've been diagnosed with colorectal cancer under age 50; and if you've had two or more primary cancers.

A genetic risk assessment will usually involve a few appointments. To start, you'll go over a risk assessment that covers both your own personal health history and your biological family's health history (if known). Typically at this appointment, blood and/or saliva samples will be collected and sent on for testing. A second appointment is usually set up to review your results.

### **Typically includes:**

- **Result:** Whether or not you have a genetic mutation that can predispose you and family members to develop cancer.
- **Test performed:** Which gene(s) sequence was evaluated.
- **Result/classification:** It will typically indicate either no mutation is detected; there's a variant of unknown significance; or there's a known cancer-causing variant. Sometimes variants are reclassified over time as more is understood about what they mean.
- **Interpretation:** Either indicates no mutation detected or suspected deleterious, which means the presence of the mutation can make a person and family members susceptible to cancers caused by the mutation.

It's critical to work closely with a genetic counselor to understand your test results. Sometimes testing is performed for one gene sequence, and other times genetic testing is performed on multiple genes. The genetic counselor will make recommendations on what to test based on your risk assessment and costs you're comfortable incurring.

*Who gets the report:* The genetic counselor; they can provide you a copy of the report during the appointment where you review your test results. Test results can take up to two to three weeks.

*Your next steps:* If it's determined you have an inherited genetic mutation that can increase your chances of developing cancer, additional family members may need to/want to be tested and/or screened for certain cancers. You will also need to undergo increased surveillance and may need to consider preventive surgeries. If you do not have a mutation, your relatives are not necessarily at increased risk, at least genetically, and they should follow the general population screening guidelines. Follow your doctor's recommendations for surveillance.

*When repeated:* In most cases, germline genetic testing is not repeated. If you're diagnosed with a second cancer, you may undergo more testing. Additionally, ask your genetic counselor about gene reclassification. In many cases, your genetic tests are kept on file and should new information about your variant be understood, you may be notified with updated results and amended reports.



## Surveillance Tests

Survivorship care involves many steps for follow-up scans. Lab work, MRIs, and CT scans may be routinely ordered. Depending on your case, ctDNA tests, which are blood tests that measure if there are any circulating tumor cells anywhere in your body, may also be ordered. Read more about ctDNA tests on page 10.

In survivorship, some survivors will always be recommended and sent off for several tests, while others drop off as the years go by. It's important to always have a doctor managing your care and to understand the ins and outs of your reports.



## MEDICAL REVIEW

Richard M. Goldberg, MD • Carmen Fong, MD, FACS

# DUDE, IT'S TIME TO QUIT TOILET PAPER FOR GOOD



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## ADVOCATING for GENETIC TESTING & COUNSELING

Genetic testing is an important part of a colorectal cancer patient's journey as it can help determine if your cancer was caused by a genetic syndrome.

This not only can impact a patient's treatment, but it can also indicate if family members are at higher risk. The National Comprehensive Cancer Network (NCCN) recommends that all colorectal cancer patients receive

genetic testing. Unfortunately, access to genetic testing and the genetic counseling that helps patients navigate the process is not universal.

### **That's where advocacy comes in.**

Fight CRC is working with our partners to advance two key pieces of legislation related to genetic testing. The first is the Reducing Hereditary Cancer Act, which would provide Medicare coverage for genetic counseling and testing for those who have not been diagnosed with

cancer, but are at increased risk. As a reminder, Medicare is the federal health insurance program for those 65 years of age and older. Passage of this legislation would ensure that individuals with a family cancer history or a known genetic mutation in the family could access genetic testing and take any necessary steps for early detection and prevention.

The Reducing Hereditary Cancer Act was introduced in the House (H.R. 1526) by Reps. Debbie Wasserman Schultz (D-FL) and Mariannette Miller-Meeks (R-IA), and in the Senate (S. 765) it was introduced by Sens. Lisa Murkowski (R-AK) and Ben Cardin (D-MD). Bipartisan members of Congress have acknowledged that patient knowledge of an inherited mutation can be lifesaving, so it is critical that patients have access to the necessary genetic testing that can empower them to take the steps they need regarding cancer screening and prevention.

Another important piece of legislation related to genetic testing is the Access to Genetic Counselor Services Act. This bill would increase access to genetic counselors by allowing genetic counselors to be reimbursed under Medicare for genetic counseling services. While the bill only applies to seniors, commercial insurance plans often follow Medicare's lead, so it is an important step toward more widespread adoption of genetic testing and counseling services.

Genetic counseling is an integral part of ensuring that patients receive the best quality care. Genetic counselors have advanced training in medical genetics and counseling and work with a patient's medical team to offer comprehensive genetic counseling services. They are able to help patients through the testing process including providing information on the benefits and risks associated with genetic testing and communicate results. Despite the importance of genetic counseling, genetic counselors are not always reimbursed for their services, making it difficult for some health systems, particularly smaller community systems, to support them.

Heather Hampel, MS, CGC is the associate director of the Division of Clinical Cancer Genomics at City of Hope and has been a strong advocate for the Access to Genetic Counselor Services Act. She said:

*"Genetic testing is typically ordered during an appointment with a cancer genetic counselor. Unfortunately, genetic counselors currently are not recognized Medicare providers, which significantly limits the ability of individuals with Medicare from receiving genetic counseling, since the cost of the appointment would not be covered. The Access to Genetic Counselor Services Act would make genetic counselors recognized providers in Medicare, which will increase access to genetic counseling and therefore testing. We appreciate everyone's support in helping us get this bill passed."*

The Access to Genetic Counselor Services Act has strong support in both chambers of Congress. The bill was introduced in the House (H.R. 3876) by Reps. Adrian Smith (R-NE) and Brian Higgins (D-NY) and in the Senate (S. 2323) by Sens. John Barrasso (R-WY), John Tester (D-MT), and Marsha Blackburn (R-TN).

The next step for both of these bills is gathering support in the House and Senate.

### **That's where you come in!**

We've made it easy for you to reach out to your members of Congress, tell them about the importance of increasing access to genetic testing and counseling, and urge them to support these bills. Get started now!



Scan to ask your representative to support the Access to Genetic Counselor Services Act.



Scan to ask your members of Congress to support the Reducing Hereditary Cancer Act.

MOLLY MCDONNELL IS FIGHT CRC'S  
Director of Advocacy

**FOLLOW MOLLY!**  
@MollyFightCRC





Ask the **EXPERT**

# cancer is **TESTING**

MY RELATIONSHIPS



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*How can I stop  
cancer from  
consuming me and  
those I care about?*

I DON'T WANT IT TO TAKE  
OVER MY RELATIONSHIPS.

---

First, it's important to know that this happens with almost everyone who gets cancer.

**It's the tornado that crashes into your life, yet it's completely normal for it to be the elephant in the room. However, you can manage its impact and that boils down to learning to set really good boundaries.**

**T**hink of boundaries as the rules that govern the functioning of our lives. When a major change happens (like cancer), we need to adjust these rules to adapt to this new reality. This applies both to myself (internal boundaries), as well as to how we interact with others (external boundaries).

In practice this frequently boils down to getting really good at clearly communicating what you need/don't need. Do you need someone to listen and be supportive—you need to say that. Do you want to just have a social night out and not talk about cancer? You need to say that too.

**The people around us are worried and often don't know what we need or how to help—it is our responsibility to tell them.**

Even with something as big as cancer, we still have to attend to our other needs. It's vital for us to be intentional about recharging our batteries. Therefore, we must carve out times to put the cancer struggles aside and try to just be normal for a while. So it is totally appropriate to say things like, "I don't really want to talk about cancer right now." Or to set the direction with "I need to recharge, so let's just focus on having a fun night."

To some degree, it's unavoidable that cancer will dominate our lives while we are in the midst of that battle. Similarly, those around us see our struggle and desperately want to help. However, with good communication and setting boundaries, cancer doesn't need to completely take over. It takes practice, and we have to be intentional about it, but this process can help us regain some much-needed balance during our fight.

## **What if my relationship ended because of cancer? How do I pick up the pieces and move on?**

**Obviously I don't know the specifics of your relationship, so I'll be speaking in general. The same basic dynamics apply for any close relationship (romantic, friendship, family, etc.). Stressful events tend to polarize relationships—they either bring people closer or tear them apart. The truth is that it probably wasn't your cancer that was the cause—more that the stress of cancer pressed upon existing problems, which caused things to fracture.**

Also, it's really important you don't take ownership for others choices. We don't make other people do things—they choose for themselves. It's a natural reaction to initially feel responsible when we have added something stressful to the relationship. But it's so important to step back and not just run with those feelings.

We are each solely responsible for the choices we make. Let the other person carry the burden of their actions.

So how do you move on? Intentionally. We grieve the loss. We lean on our support systems. We refocus on our own health and embrace the things in our lives that fuel us. Passions and hobbies. Growth and learning. Connection with those who do choose to walk with us during difficult times. Seek gratitude and small pleasures. Life might hurt right now, but there is beauty and opportunities all around us. Don't look backward, embrace the only thing that truly exists—this moment and your power to make it good.

**You'll get through this—you always do.**



**CHAD LATTA, MA**

Shrink, professor at Metro State University (Denver, Colo.), painter, BJJ black belt, USMC vet, stage III survivor, and frickin' hilarious. Contact Chad at [chadlatta.org](http://chadlatta.org) or at [chadlatta@hotmail.com](mailto:chadlatta@hotmail.com).

# tested *by* grief



By

**CAROLINE  
JOHNSON**

**There are moments in life that will stop you in your tracks, moments where you can't breathe or move.**

I've experienced many of these moments: the birth of a child, the moment I said, "I do" at the altar. I've also experienced moments where doctors were yelling, and I was being asked so many questions that my head was spinning, but everything around me was completely muffled, and nothing made sense. The life I knew was just forever changed. My spouse died. His pain and suffering was over, but mine began.

Abandoned. Lost. Angry. Broken. Six years ago, this was a moment I found myself in. I was thrown into a new position: The sole provider for my family and a widow at age 42.

My husband Scott had just passed away from stage IV colon cancer, and it was up to me to raise our three little boys who were trying to wrap their little heads around the fact that their father would not be coming home.

I wanted to emotionally unplug myself from the world, and I tried to shut people out, but it was impossible. I had a lot of questions and wondered why God, who is supposed to love us unconditionally, allowed pain and suffering to be inflicted on those we love. Watching life leave a body is not for the faint hearted. It is downright scary.



Scott Johnson was diagnosed with stage IV colorectal cancer on April 29, 2015. He was healthy, rode his bike 30 miles on his days off, was an avid runner, did not smoke and had no family history of cancer.



Scott was a family man, firefighter, and U.S. Coast Guard veteran.

Scott's life ended two years and four months after the date of his diagnosis. Scott passed away from colorectal cancer in 2017 at age 46.

### But what was scarier was having to move forward while my heart was breaking.

As I reflect over the past six years, I realized God never directly answered my questions. But, people and circumstances have helped heal my heart. From the dragonflies that swarm me during the summer months to one of my boys doing or saying something so eerily familiar (just like their father would have), it makes the hairs on the back of my neck stand up. Just because we've made it six years doesn't mean we don't feel the kick in the gut anymore—especially when there's the absence of a father at the baseball field. But as the anniversary of his passing came, I didn't do what grief wanted me to do: lay in bed most of the day. Three insanely crazy boys didn't allow me to do that. Instead, we celebrated Scott's life and fully embraced the day.

### LESSONS ON GRIEVING

Grief has tested me over the years, and the scab over my heart continues to heal. Some days I want to pick at it, and some days I do. I've learned there is no right or wrong when it comes to grief. Everyone deals with grief in their own way. Some cry; some get angry; some laugh uncontrollably because the pain is simply too much. Others completely shut the world out.

Trying to find a silver lining and put on a brave face has been extremely difficult. Initially after Scott died, I grieved privately, mainly because every time I broke down, the boys couldn't handle it. The shower was my best friend. I could cry until I had nothing left, and if my eyes were red when I got out, that little white lie of "I got shampoo in my eyes while I was washing my hair" always worked like a charm. There were no late-night calls to friends or that dreaded breakdown at the funeral. Don't get me wrong,



I lost my composure at certain points, but those bigger moments happened behind closed doors.

Grief is like the biggest roller coaster ride you have ever been on. That phrase "It will get better, just give it time," is a joke. I was angry and resented those around me who kept telling me it would be OK. OK? Nothing about my husband dying is OK.

Year one after he passed is pretty much a blur, and year two was a doozie. I had to face the harsh reality that he was never coming back. The "year of firsts" was over. No more funeral arrangements, no more dinners, no

Sons Zackary and twins Jacob and Benjamin continue to advocate alongside Caroline in Scott's memory.



**We all know we can't take life for granted because tomorrow is never promised. We are here on borrowed time.**

I have worked and focused on living the best possible life each day. Each day I get to spend time with my boys is another reminder of how much Scott has missed. Some days are easier than others, and I would be lying if I said they are all fabulous. I don't always see unicorns and rainbows, but I try to not let insignificant and mundane issues dictate how I live. After all, life shouldn't be that serious, should it?

more dodging telephone calls from friends and family to "check in." Year two was a harsh reality. By year three though, the pain began to ease. It took three years to even think about putting myself back out there to meet someone new and date. This is different for everyone, but I needed to make sure I was emotionally and mentally prepared for the possibility of welcoming someone new into my life.

## LESSONS ON LIFE

You know that saying, "Live life to its fullest!"? I would ponder that phrase late at night when I couldn't sleep and at times I thought, "What a bunch of crap. What about when your entire world just crashed all around you?" But, over time, I have changed the way I see things.

Little things that used to drive me nuts no longer affect me. Dishes in the sink? Wash them later. Burnt dinner? Order out. Dead car battery? Call AAA.

## LESSONS ON LETTING GO AND MOVING FORWARD

Let me be completely blunt: I hate the phrase "Letting go." To me, letting go means you are starting to forget the life you had before. I am here to tell you as a widow, you will never, ever forget. Our memories are filed away, and we will always face triggers that send us back to moments we remember. We never forget, even when we wish we could.

While I will never embrace the idea of letting go, I have experienced that the farther out I get from the moment of loss, the more the pain starts to ease up. Grief is not fatal, but sometimes it feels like it is. Scott's death left a void, but his death made me who I am today and if it was not for this death, I would not be where I am at this moment in my life. Helping patients and caretakers navigate the uncharted waters of cancer can at times be grueling, but also can make for some of

the most rewarding moments. I am grateful for the life I had with Scott and for the one I have now because I am moving forward in such a positive direction.

Remember: Someone who has been touched by grief and loss will laugh and smile again, and if they are lucky, they may even love again. This is moving forward, but it does not mean they have moved on. Our loved ones do not disappear as pain diminishes, but rather, we learn to live with their memory, and the memories of our life, in a slightly different way.

You're not alone as you navigate loss and grief.

If you've lost a loved one to colorectal cancer, connect with others in our Community of Champions grief group, available on desktop or app.



**SCAN TO GET THE APP**





MEDICALLY REVIEWED  
**RESOURCES**  
*you can trust*

## Hot off the Press

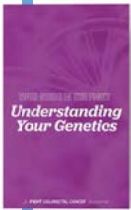
Check out the newest resources we've just added to our Resource Library!



### NEW VIDEOS

Learn about surgery options for

colorectal cancer patients and the advantages of robotic surgery. Watch our new video that breaks down biomarker testing and who it's for.



### BROCHURES

Discover more about genetics, skin toxicities, and early-age onset colorectal cancer in our new brochures.

### TRANSLATIONS



The Fight CRC website can now be translated into Spanish and Chinese, and brochures are

also available in these languages.



### GET RESOURCES

To check out our free patient resources and more, visit [FightCRC.org/Resources](https://fightcrc.org/Resources) or scan this QR code.

# YOUR GUIDE *in the* FIGHT



## Meetups

Your Guide in the Fight Meetups are online gatherings open to anyone within the colorectal cancer community: patients, caregivers, loved ones, and medical professionals. Everyone is welcome.

**Wherever you are in the colorectal cancer continuum, someone understands exactly what you're going through.**

We offer a variety of monthly meetups: whether you are an early-age onset survivor, recently diagnosed, or want to check out the hot topics we are discussing each month. The goal of each meetup is to engage you and meet you where you are at, while connecting you with a supportive community!

All meetups foster an environment of compassion, camaraderie, and understanding. They provide a safe space. They will empower and educate you. Don't miss the opportunity to connect with fellow survivors, enhance your understanding of colorectal cancer, and explore all the themes shaping our collective journey toward a brighter future.



### ATTEND A MEETUP

Scan to see upcoming dates and reserve your spot at an upcoming meetup.



## Waiting Room Materials

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

Or are you a patient wanting to connect your medical team to Fight CRC? Reach out for our brochures, magazines, and posters to put in your office. Available in English, Spanish, and Chinese. Contact [zac@fightcrc.org](mailto:zac@fightcrc.org) for details.



# understanding insurance

## Insurance is a critical piece to getting medical, dental, and vision tests and scans.

Your insurance plan, also called a benefits plan, will dictate whether you will need prior authorization (insurance approval before the procedure or test); what types of exams are covered; and how frequently you may have them. The formulary dictates what drugs are covered and what you owe for the drugs, excluding your copay and coinsurance.

You typically have options when it comes to insurance. Employer-sponsored means your employer offers you and/or your spouse and dependents a benefits package as a part of your compensation. Oftentimes these plans are offered by commercial insurance companies, such as Blue Cross, Aetna, UnitedHealthcare, Kaiser, etc. During your employer's open enrollment, they will explain the plans available for you to choose from. Ask when your benefits will begin. You don't have to enroll in your employer's plan, but, sometimes your employer is willing to pay a portion of your premium, which reduces your health care costs.

If employer-sponsored benefits are not an option for you, you can check the Healthcare Marketplace, which was made possible by the Affordable Care Act. Open enrollment for the Marketplace is November 1 through December 15, and coverage begins January 1. Based on your age and income, you may also qualify for Medicare or Medicaid plans.

Typically, you choose health insurance plans during open enrollment, unless you qualify for a special enrollment due to a qualifying life event. These qualifying events include losing your benefits, marriage/divorce, having a baby or adopting, or if your household income shifts.

When shopping for a benefits plan, here are a few things you want to look into:

**In-network coverage:** The benefits company will have a list of in-network providers and health care systems. Check to see if your medical team and preferred hospitals are included.

**Continuity of care:** You may be able to continue to see your current doctor or therapist for a specified period if you must switch plans. This can be crucial if your scans overlap when you have to change your plans or doctors.

**Additional services:** Check for coverage for services like physical therapy, mental health, and holistic care. If you need medical supplies, like ostomy supplies, ask about your quantity limits and expected costs.

**Premiums/deductibles/out-of-pocket maximums:** How do the figures on your available plans align with your anticipated medical expenses and what can you afford? If you're anticipating surgery, treatments, colonoscopy, and/or imaging in the future, you may want a benefits plan with a lower deductible or out-of-pocket maximum, even if the premium is higher. If your follow-up care has slowed down, you may consider a higher deductible, or out-of-pocket maximum and lower premium. While cancer teaches us to expect the unexpected, choose your benefits package based on the information you have now and the security you need for the future.

## GETTING INSURANCE HELP

Insurance can be overwhelming. If you are not sure how to navigate it, there are (free) insurance brokers that can help you select the right plan if you tell them what is most important to you in your coverage. And if you're stuck, reach out to our community for help and resources.

## BASIC INSURANCE TERMS TO KNOW

**PREMIUM:** The cost of your insurance policy.

**DEDUCTIBLE:** What you must pay before your insurance benefits cover costs.

**OUT-OF-POCKET MAXIMUM:** The most you'll pay for covered services in a calendar year. Many survivors hit their out-of-pocket maximums each year.

**COPAY:** What you pay right away when you check in at the doctor's office or pick up a prescription. This is determined by your insurance plan.

**CLAIM:** Paperwork submitted to your insurance company each time you use your benefits. Typically your doctor's office or medical facility will submit the claim on your behalf.

**EXPLANATION OF BENEFITS:** Sent by your insurance company telling you what was billed to your insurance; what insurance paid; and the estimate of what you'll owe. This is NOT a bill.

**IN-NETWORK:** Doctors and facilities that have a contract with your insurance company; typically your costs are lower since insurance will cover more of their fees.

**OUT-OF-NETWORK:** Doctors and facilities that do not have a contract with your insurance company. You can submit the claims to your insurance company, but you will likely owe more, since insurance won't cover as much of the cost.

**LIFETIME MAXIMUM:** The maximum amount your insurance plan will pay during your lifetime.

**PRE-EXISTING CONDITION:** A health condition you had *and knew about* before you enrolled in your medical plan.

**APPEAL:** If your insurer denies your claim or refuses to cover a procedure/scan/test your doctor orders, read the denial letter carefully for the reason why. You can work with your doctor to follow an appeals process and request that the insurance company reconsider.



**PHUONG GALLAGHER**

Research Advocacy Manager, Fight Colorectal Cancer

**FOLLOW PHUONG!**

@CancerInsider



# YOUR GUIDE IN THE FIGHT *Clinical Trials*

## *What Is a Clinical Trial?*

You have a backache after a day of yard work—what do you do? Pop an ibuprofen and wait a few minutes. Flu season hits, and you want to avoid it. You go get a flu shot.

From over-the-counter drugs to prescription drugs and vaccines, all of our modern medicines have been thoroughly investigated and researched. The Food and Drug Administration (FDA) is the regulatory organization that ensures medications in the U.S. are safe and effective for consumer use.

**How do they know what's safe? They learn through clinical trials.**

## *Types of Clinical Trials*

There are lots of different kinds of trials that need participants every day.

**Clinical trials test new ways to:**

- Prevent colorectal cancer
- Find and diagnose colorectal cancer more effectively or earlier
- Treat colorectal cancer
- Manage symptoms or side effects of colorectal cancer






If you're interested in advancing science and getting involved, there's probably a trial available to you. The good news? Your participation is what advances research and makes scientific breakthroughs. Without you, we would not make progress in the fight against colorectal cancer.

## *How Do Clinical Trials Work?*

Before new treatment can even reach patients enrolled in clinical trials, they go through a rigorous pre-clinical research phase. During this phase, the drug or treatment is studied in laboratory animals for safety and efficacy.

The goal of clinical trials for treatment is to make cancer treatment individualized, with fewer side effects, so people can live longer with a better quality of life, and ultimately to find cures.

Researchers and doctors follow strict guidelines to protect trial participants while collecting information to assess medical protocols, treatments, medical devices, and more. They do this to learn if these clinical trial drugs work and if they are safe.

Pre-Clinical	Phase 1	Phase 2	Phase 3	Phase 4
				
Not done on humans.	This phase focuses on the <b>safety</b> and proper dose.	This phase focuses on <b>effectiveness</b> and side effects.	This phase compares the <b>new treatment</b> to existing treatment.	Now, treatment is <b>approved and available</b> . Long-term side effects are observed.
⌚ Takes about 6 years	⌚ Takes about 1 year	⌚ Takes about 2 years	⌚ Takes about 2 years	⌚ Takes about 5+ years
Average Number of Trial Participants: <b>5-50 people</b>		<b>Less than 100 people</b>	<b>Hundreds of people</b>	<b>Thousands of people</b>

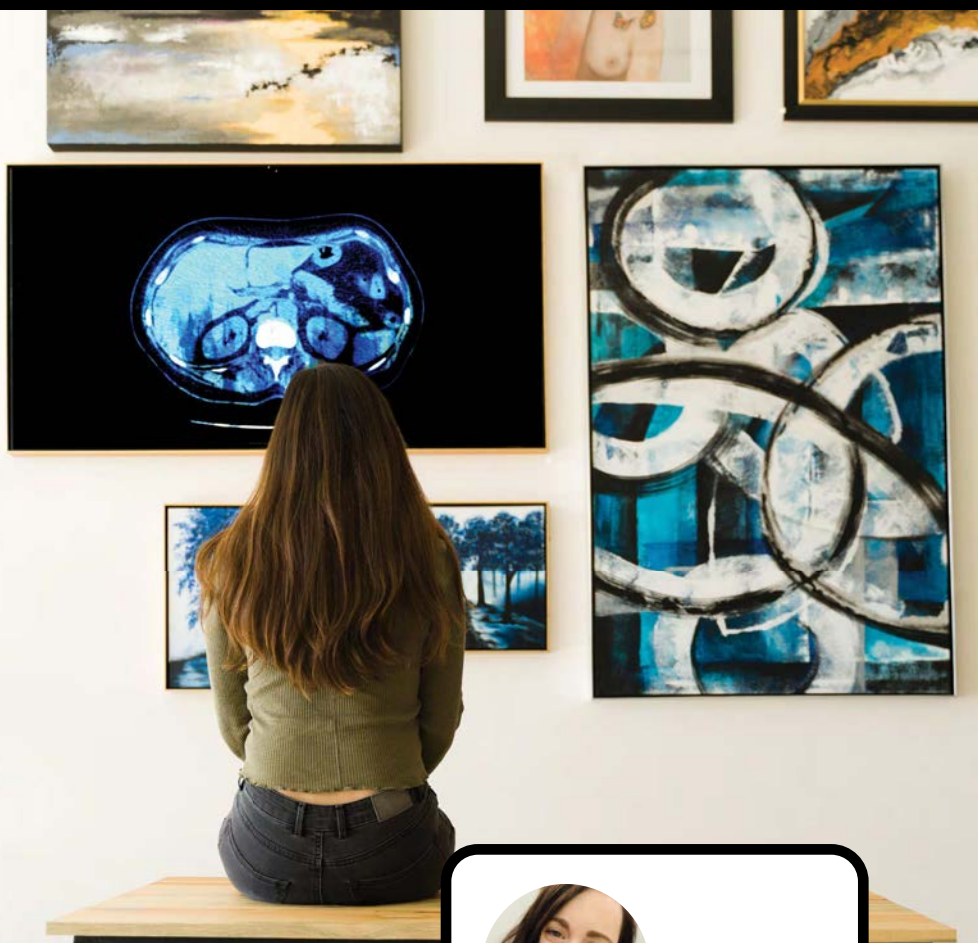


### FIND CLINICAL TRIALS

Looking for clinical trials that are relevant to the colorectal cancer community? Find a curated list of trials sourced daily by trained research advocates at [TrialFinder.FightCRC.org](https://www.trialfinder.org).

Q:

**What is one thing you do that helps you handle scanxiety?**



**JJ SINGLETON**

STAGE IV SURVIVOR  
*Waynesville, N.C.*

Having that one person that you could just turn to that gets it and understands you and what you're going through. Also escaping into movies, TV, or books for me, especially "Star Wars."



**PHILLIP DAWSON**

STAGE IV SURVIVOR  
*Kansas City, Mo.*

I may be wrong for saying this, but I've really overcome anxiety by understanding I've already dealt with the hard part. After "X" amount of chemotherapy sessions, scanning isn't as scary.



**REAGAN BARNETT**

STAGE II SURVIVOR  
*Mobile, Ala.*

I turn it into a vacation day... I used to travel for my scans, and I'd go to a museum or something fun to make it something to look forward to.

**SCANXIETY**

**Scanxiety is "scan anxiety": when you feel anxious about upcoming cancer scans.**





**SHANNON LEE-SIN**

STAGE III SURVIVOR  
*Miami, Fla.*

I remind myself that no matter what happens, it can't be worse than what I've been through. It can only be more of the same. It can't be worse, because even if it is, I have more experience and knowledge than I did before. And I already got through it once. Also, I prepare for the worst, but keep my hope and expectation for the best!



**LISA BENNETT**

STAGE II SURVIVOR  
*Rochester, N.Y.*

I've stopped fighting it. I allow myself to feel anxious, and I breathe. As my therapist says, "Accept what's real." What's real is that I'm terrified that doctors will find cancer again and nothing is going to change that for me. So I lean in. I pray, and I focus on my breathing.



**JOANN SIMMS**

STAGE II SURVIVOR  
*Bristow, Va.*

I plan something to do that brings me joy (concert, dinner with a friend, a trip) shortly after the scan so that regardless of the scan, I have something to look forward to.



**RISSA DODSON**

STAGE III SURVIVOR  
*Valley Village, Calif.*

I listen to a song called Weightless by Marconi Union. It's been studied by neuroscientists and is called the most relaxing song in the world. It lowers blood pressure and reduces heart rate. And I deep breathe peppermint oil.



**LETICIA HERRERA  
ALVARENGA**

STAGE III SURVIVOR  
*Austin, Texas*

Binge a show I've watched 1000 times.



**HEATHER HARDECOPF**

CAREGIVER  
*Plano, Ill.*

My husband handles his own scanxiety pretty well with hugs and Xanax® for about 36 hours. Then, I'm on the phone with the doctor, nurses, receptionist, anyone who will listen, begging for results ASAP.



**GREG VAUGHN**

STAGE IV SURVIVOR  
*Overland Park, Kan.*

Go flying!



**READ**

Scan to read more tips on how to handle anxiety when you're facing tests and scans.

# 49,000+

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

The Trial Finder is a one-stop place to search for and learn about high-impact research studies for colorectal cancer patients. One click away from the Clinical Trial Finder is the Provider Finder, a digital tool that helps patients find oncologists, radiologists, surgeons, and gastroenterologists.

We're delivering on our mission to provide patients with the education and resources they need to find the best treatment options and providers for them, as well as support innovative uses of data and further groundbreaking research.

### SEARCH TRIALS BY:



### SEARCH PROVIDERS BY:



SCAN HERE  
for Clinical Trials

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



SCAN HERE  
for Provider Finder

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



# patient privacy

## Do You Share Your Test Results Online? Why or Why Not?



### **Ashley Pedro**

*Stage IV Survivor  
Albion, Neb.*

**“I do as it’s a way of sharing with a bigger group of people rather than talking to people individually.**

It also helps narrow down the amount of questions. I do share a lot more now since I am in a clinical trial, as I don’t think there is enough information out there on clinical trial experiences that I’ve found. I also do it because I am and have been a firm believer of advocating for yourself. For example, I’ve had headaches for several months now and have had two (including the most recent) CT scans. Now they [my treatment team] feel as though there is a bigger issue. If I wouldn’t have mentioned it or made it out to be a bigger deal, it probably would have been looked over without any more thought.”

### **IF YOU CHOOSE TO POST:**

- Check your privacy settings and set them at a level you’re most comfortable.
- Make sure personal information is not included, things like: your birthday, Social Security number, address, phone number, and insurance plan ID.
- Avoid sharing misleading information by explaining in the post what your doctor said the results mean.
- Share your story in Fight CRC’s Champion Stories to help others facing similar situations find community and hope.

YAY



### **Julie Brown**

*Stage III Survivor  
Boxborough, Mass.*

**“I used to. But now I set boundaries for me and my family.**

We like to process together and privately before sharing things. Plus after years of fighting this battle, when I have good results, I have survivor’s guilt and feel guilty sharing the news especially after having so many friends struggle with their fights with cancer.”

### **IF YOU CHOOSE NOT TO POST:**

- Save your test results in a place where you can access them again if needed.
- Surround yourself with a small community who can support you offline, and both celebrate the good news and mourn the sad news with you.
- Remember: Fight CRC’s Community of Champions is a safe space where you can connect with others, and also share as much or as little as you’re comfortable with.

NAY



# Upcoming Events



## LOOKING AHEAD

### NOVEMBER

#### **Gratitude Month & Family Health History Month**

Get your free gratitude journal at [FightCRC.org/Gratitude](https://FightCRC.org/Gratitude).

### DECEMBER

#### **Declare March as Colorectal Cancer Awareness Month in Your State**

Get your state to participate in Colorectal Cancer Awareness Month in March 2024 by asking your governor to issue a state proclamation or letter of support! Proclamation request materials will be available early December.

### FEBRUARY

#### **Black History Month Chinese New Year**

### MARCH

#### **Cologuard® Classic** *in Tuscon, Ariz.*

#### **Call-on Congress** *in Washington, D.C.*

## A NIGHT *with* THE STARS



### ATTEND

Scan to get tickets to attend our DISCO-themed evening!

Friday, October 27, 2023  
*Springfield, Missouri*

During this third-annual event, we will recognize the dazzling stars of the colorectal cancer community: patients, survivors, and caregivers. The collective light of these stars burns bright as we celebrate and remember our relentless champions of hope.

## Early-age Onset Colorectal Cancer THINK TANK

Friday, December 1, 2023  
*Nashville, Tennessee*

Fight CRC, Vanderbilt, and the National Cancer Institute are coming together to establish a transformative think tank,

amplifying research efforts for early-age onset colorectal cancer (EAO CRC). By convening thought leaders from industry, academia, advocacy, public health, government agencies, and patients and caregivers, this collaborative initiative aims to catalyze progress in addressing this unsettling phenomenon in colorectal cancer.

This influential think tank will host presentations and discussions led by world-renowned scientists, focusing on the current state of EAO CRC research and identifying crucial knowledge gaps. By exploring prevention and treatment strategies for young adults with colorectal cancer, this collaborative effort seeks to translate ideas into actionable solutions.

**The event is not open to the public**, but follow **@FightCRC** on social media for updates and highlights.

**THANK YOU TO OUR SPONSORS WHO SUPPORT THIS  
MAGAZINE AND THE EDUCATIONAL CONTENT IN THIS ISSUE.**



# Time to Flex a #StrongArmSelfie

Show your support for the fight against colorectal cancer by snapping a #StrongArmSelfie.

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

## Here's How It Works

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



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



FightCRC.org



Fight Colorectal Cancer



@FightCRC



@FightCRC



@FightCRC



**Groups**

Fight CRC's Climb for a Cure  
ADVOCATES at  
Fight Colorectal Cancer



@FightCRC





**Read The Colon Club's story in Molly's book, "One Drop of Rain"!**

## Molly McMaster Morgoslepov

**A**fter being diagnosed with colon cancer on her 23rd birthday in 1999 and told she may be the only patient in the country, or the world, facing the disease so young, Molly McMaster Morgoslepov set out to do something about it.

In 2000, she in-line skated from New York to Colorado to raise awareness. Two years later, she developed the Colossal Colon, nicknamed "Coco," a crawl-through replica of the human colon that the inflatable colons today are modeled after. As Coco toured the country, a stage IV survivor diagnosed in her 20s—Erika Bilger—came to see it and meet Molly. She tossed out the idea of doing a calendar with young patients. In 2003, The Colon Club was officially formed, and projects like *The Colondar* (which became *On the Rise* magazine) and Colon Talk—online message boards, were born.

For the past 20 years, The Colon Club has stuck to its mission of raising awareness in attention-grabbing ways. But it has also uncovered its magic: connecting young survivors who need support, healing, and hope.

Now a 20+ year survivor, Molly continues to inspire. As part of the merger between The Colon Club and Fight CRC, Molly is now a voting member of Fight CRC's Board of Directors.

### THE COLON CLUB *Fun Facts*

- Founded in 2003, The Colon Club was one of the first organizations to bring attention to early-age onset colorectal cancer.
- The annual photo shoot turned into what's now known as Colon Camp.
- For the majority of its 20 years, The Colon Club was run by a team of passionate volunteer staff.
- 230 people have had their stories featured in one of The Colon Club's publications (*The Colondar*, *Colondar 2.0*, and *On the Rise* magazine).
- The Colossal Colon was featured on the Today Show with Katie Couric, Jimmy Kimmel LIVE!, Shipping Wars, Playboy, and others.

### WHAT NOW?!

The Colon Club and Fight CRC have begun operating as one organization, and The Colon Club is a program of Fight CRC focused on supporting and connecting young adults.

**Leading the charge are past models from The Colon Club.**



#### **Danielle Ripley-Burgess**

*Fight CRC Chief Storyteller  
2009 Colondar Model  
Stage III Survivor*

Managing strategy and providing overall insight and direction for The Colon Club, which is now a program of Fight CRC.



#### **Carole Motycka**

*Fight CRC Project Manager  
2020 On the Rise Model  
Stage IV Survivor*

Overseeing the day-to-day management of The Colon Club



Many people who've been a part of The Colon Club have made a significant impact in the colorectal cancer community.

Here are a few who have pioneered projects and organizations:



**Phuong Gallagher**  
served as The Colon Club president



**Candace Henley**  
founded Blue Hat Foundation



**Dave Dubin**  
founded AliveandKick'n



**Kim Troisi-Paton**  
(pictured left) started fundraiser that is now The Kimberly Fund

**Anita Mitchell**  
(pictured right) came up with Dress in Blue Day.



**Trish Lannon**  
served as The Colon Club president



**Chris Ganser**  
co-founded Fight CRC's Climb for a Cure



**Brian Threlkeld**  
co-founded Fight CRC's Climb for a Cure



**Tom Marsilje**  
established Fight CRC's Clinical Trial Finder

## Ways to Give

### ONLINE

**Give.FightCRC.org** or email **roxanne@fightcrc.org**

### CHECK

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

### CALL

(703) 548-1225, ext. 10

### STOCK & ESTATE

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

### SHOP

**Shop.FightCRC.org**

### IN-KIND

To donate products for our events and care packages, contact Katie Hawkins at (703) 647-4693, ext. 814 or **katie@fightcrc.org**

### EMPLOYER MATCHING PROGRAM

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

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

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



## FIGHT COLORECTAL CANCER

134 Park Central Square, Suite 210  
Springfield, MO 65806

*Celebrating more than*  
**\$1,000,000**  
*raised for colorectal cancer research!*

Born from the vision of Chad Schrack, Brian Threlkeld, and Chris Ganser (pictured right) in 2016, Climb for a Cure began as a powerful ascent up Longs Peak.

Today, having raised a milestone **\$1,000,000**, we continue to climb in memory of Chris and all those we've lost to colorectal cancer, and in honor of those fighting today. Stand with us, donate, and be part of funding transformative research grants, empowering programs, and invaluable educational resources for patients and their loved ones.

### THANK YOU 2023 HOSTS & SPONSORS

*Nearly 400 champions hosted events all over the country raising more than \$250,000!*

#### MARY BETH KROPP

##### CALIFORNIA CLIMB HOST

HER TEAM RAISED MORE THAN \$38,000 IN 2023

"As a Climb for a Cure host, I get to feel — at least for one day every year — the love, the encouragement, and the support for my boys and me."

#### WENDY HARPP

##### NEW YORK CLIMB HOST

HER TEAM RAISED MORE THAN \$21,000 IN 2023

"I Climb to lend support to those who need it and spread awareness. It's so comforting to know you are not alone."

#### RYAN VIETH

##### COLORADO CLIMB HOST

HIS TEAM RAISED MORE THAN \$13,000 IN 2023

"I'm passionate about the fight because the last four years of my fight have been incredibly difficult, but I made it through. Seeing younger people fight this disease makes me want to give what I can to others."

★ THANK YOU 2023 SPONSORS ★

TAIHO ONCOLOGY

MERCK

EXACT  
SCIENCES

natera

GUARDANT

NO SHAVE  
NOVEMBER

