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Volume 15

**ISSUE 1** 

**Stronger Together** 





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#### **DISCLAIMER**

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

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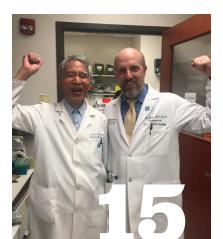
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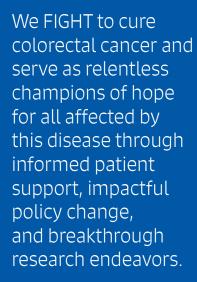
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Tribute gifts made in honor and in memory of colorectal cancer survivors and fighters





Learn more at FightCRC.org





## Best relationship advice for patients and caregivers fighting cancer?



When giving support to a cancer patient, be positive. Take one day at a time, don't look too far forward. For example, if a patient is in treatment, instead of counting ahead 12 sessions, focus on the recovery from the most recent treatment.

MICHAEL TOMKO Stage III survivor

LISTEN TO OUR PODCAST with MICHAEL!



Practice patience.
Cancer will change the patient and the caregiver in different ways. Use open communication because the scale of vulnerability will sway.

YASMEEM WATSON Stage III survivor



Communicate and show gratitude. If you value something about your partner, say it. Don't be afraid to be vulnerable.

WENDI GEORGE HAWKINS Caregiver



The diagnosis is so much more than just physical. Both patient and caregiver will go through so much mentally and emotionally. Try to support each other through the battle.

**DAWN BLATT**Stage III survivor



You will do things for your partner that you never could have imagined. You need as many advocates as you can find. Take time for yourself and don't feel slighted when the patient wants to be alone every now and then.

ANNA BOYLE SQUITIERI Stage III survivor



You will learn what intimacy really is, what it means to love till death do us part. You will learn to cherish every moment and turn every opportunity into a memory that your loved one can forever hold on to.

**FREDERICK SCHILLER**Caregiver

TELL US

#### **HOW DO YOU PLAN TO LEAVE A LEGACY?**

Email danielle@FightCRC.org to share your ideas and for a chance to be featured in the fall issue!



#### **ABOUT THE EDITOR**

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

#### **FOLLOW DANIELLE!**

@DanielleisB







#### **Stronger Together**

I don't cry often, but one breakdown I'll never forget is the day I was in a virtual meeting with Fight CRC's President Anjee Davis and I lost it.

Technically, she was my boss at the time. But she was also a friend, and the emotional toll of facing colorectal cancer professionally and personally had become very heavy. My strength completely collapsed and my tears told the real story. I was struggling.

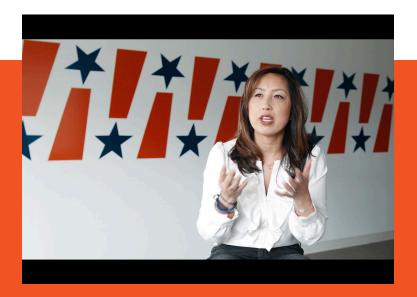
Anjee stopped everything across the screen to listen, affirm my struggle, and challenge me to put my health first. She encouraged me to reevaluate my boundaries, set limits, and take time to reflect on what I needed as a survivor. It was powerful and healing. Neither one of us expected that a few years later, the tables would turn. This past February, she was diagnosed with early-stage breast cancer and I became one of her many friends to help her face it.

No one fights alone. This is a popular phrase and hashtag around Fight CRC. We've carried this up Capitol Hill steps, to the tops of mile-high mountains, and across our screens during a global pandemic. And truly, we mean it. We are healthier and more relentless when we accept support. Even in a world of social distancing, we come together. As we head into spring and summer, which will undoubtedly be full of more changes and new normals, may we remember that although challenges come, we're stronger when we choose to be vulnerable and accept support. We are stronger when we fight together.

STAY STRONG.

Danulle Ripley-Buggess

Editor & Two-Time Survivor



## Watch Anjee

Share her story about being diagnosed with early-stage breast cancer earlier this year.



In October 2019, PGA Tour **Professional Golfer Tom** Lehman went to Washington, D.C., to share his story of surviving stage I colorectal cancer with policymakers.

He met with Members of Congress and their staff, and he even had the opportunity to meet with the president. He discussed the importance of access to timely colorectal cancer screening and his efforts were successful! A few months later, the administration announced that it was supportive of policy to close the so-called "Medicare" loophole" to ensure that seniors do not face out-of-pocket costs if they go in for a screening colonoscopy and polyps are removed. Additionally, this past March, the president issued a proclamation declaring March as Colorectal Cancer Awareness Month.

THANKS TOM FOR BEING SUCH AN amazing ADVOCATE!

#### STATE-BY-STATE ADVOCACY F!GHT COLORECTAL CANCER

Learn MORE

#### State Advocacy

Advocacy isn't just federal for us, it's getting local! This spring we launched the Catalyst State-by-State Advocacy Program. The program aims to accelerate progress toward turning aspirational colorectal cancer screening goals into reality by increasing access and reducing barriers at the state level.



**DR. JOSE PEREA** Jiménez Díaz Foundation University Hospital

The WORKGROUP

#### **Tackling Early-Age Onset Colorectal Cancer**

Fight CRC hears the urgency from our community to better understand early-age onset colorectal cancer, and we're doing something about it.

Through dedicated advocacy efforts, we've started to work with key players in this field such as the Department of Defense (DoD) and the National Cancer Institute (NCI) to address the rise in young-onset colon and rectal cancers. We're also working with international groups to address the rise from a global perspective.

The workgroup will reconvene virtually in June 2020 with partners from more than twenty countries for the second Early-Age Onset CRC International Symposium, hosted by Dr. Jose Perea of the Jiménez Díaz Foundation University Hospital in Madrid.

#### RESEARCH proves **SUPPORT MATTERS!**

A recent study on women and social support backed up what researchers already presumed: There's a role for social support when it comes to patients with serious illness.

Amongst women who reported low social support, there was a higher mortality from colorectal cancer specifically. "These findings support the idea that women who have supportive friends and family around them when they are diagnosed do better," said Candyce Kroenke, MPH, ScD, a research scientist with the Kaiser Permanente Division of Research.

READ the ARTICLE



#### **DID YOU KNOW?**

Women who have supportive friends and family around them when they are diagnosed have better outcomes.







Palliative care supports people living with colorectal cancer.

A cancer team focuses on treating or curing the source of the cancer. A palliative care team works to understand your goals of care, what gives you joy in your daily life, and ways to have the best quality of life possible. Palliative care doctors are specially trained in communication skills—how to interact with you and your caregiver or family, as well as coordinating with your other doctors.

Palliative care specialists have expertise in symptom management and can help address side effects from surgery, radiation, or chemotherapy, and symptoms from the cancer itself. They aim to reduce the need for emergency room visits and hospitalizations. For example, colorectal cancer patients often have surgery that removes part of the bowel, which can lead to disruption in bowel habits, abdominal pain, and cramping. Sometimes ostomy surgery is needed, which is when the intestine is brought through an opening in the skin so waste can be emptied into an external

bag. This surgery and related symptoms can significantly impact one's quality of life. A palliative care team can help manage the symptoms and provide support in coping with this life-changing situation.



The sooner, the better for getting connected to palliative care.

The American Society of Clinical Oncology (ASCO) recommends patients with advanced cancer get connected with palliative care early in the disease course,

## Hometown

HOW SUPPORT from FRIENDS, FAMILY, & FANS HELPED

Hockey Fights Cancer Ambassador AND Stage III Survivor EDDIE OLCZYK BEAT the ODDS

#### Feature **STORY**

People told Eddie he would not make it at a lot of things as an athlete, and he proved them all wrong. But not one person told him he would lose his battle with cancer. Instead they told him he would beat it.

"That was the greatest support I've had and something that will stay with me for the rest of my life."



## ockey bumps or aging. Initially, that's what Eddie Olczyk thought he was experiencing as dull abdominal pains began.

Aches and pains were commonplace for a pro hockey player who'd been on the ice since age six and played in five world championships, three Canada cups, the 1984 Olympics, not to mention thousands of games in between.

Yet at age 51, still in great shape and never a drinker or a smoker, he soon learned cancer doesn't play by the rules. Increasing pain and constipation led Olczyk to ask his best friend Dom to bring over Metamucil since his family was out of town. When that didn't help, Dom drove him to the ER where one thing led to another and the unexpected news: He had stage III colon cancer.

Telling his wife Diana, college-aged kids, parents, brothers, and friends were difficult first steps, yet 10 days later, Olczyk knew it didn't stop there. Although he would have rather crawled under a rock, his scheduled

appearances as a retired Blackhawks player and current NBC commentator meant his story would go public—quickly. So, he worked with the Blackhawks to issue a press release and control the message.

"I was afraid of letting down my employers, NBC, the Blackhawks, my family—especially my kids," Olczyk said. "But, I felt better once it became public. It was a weight off my shoulders. I'm sick. Everyone knows. Now, I'm going to focus on getting better and healthy."

Once the news hit, both his family and hometown fans weren't going to let their beloved "Edzo" fight alone.

#### SON OF CHICAGO

A "son of Chicago" as Rep. Mike Quigley referred to him as he told about his cancer from the House floor, Olczyk grew up in the suburb of Niles with loving parents and two brothers. Their supportive family values instilled the value of hard work, dedication, and integrity, which helped him learn perseverance early on, especially when many doubted his hockey career.

#### Hometown **HERO**

Thanks to his family's unending support, he went on to shock everyone when he became the youngest player to make the U.S. Olympic hockey team at 16 years old, and the first Chicago-born player to be drafted by the Blackhawks.

"While I was extremely emotional and cried [when drafted by the Blackhawks], I also jokingly referred to North Carolina star Michael Jordan, who had been drafted by the Chicago Bulls, also third overall," said Olczyk. "This was the first and only time Eddie Olczyk and Michael Jordan were mentioned in the same sentence."

Olczyk would go on to play center for 16 seasons with the Blackhawks, Penguins, Maple Leafs, Jets, Rangers, (the 1994 Stanley Cup champions) and Kings, as well as serve as the Penguins' head coach for two years before retiring as one of the top Americans in National Hockey League (NHL) history in terms of goals and total points. Fate (as well as a broadcasting opportunity)

returned him to Chicago where he found success in media and became an Emmy Award-winning television commentator for the NHL and horse racing. He was inducted into the U.S. Hockey Hall of Fame in 2012.

Yet as his fame, awards, and accolades grew, there was one thing that made him most proud, the one reason he was determined to fight colon cancer: his family.

#### TEAM EFFORT

"I was at peace when I was sick because the most important people in my life knew how I felt about them... I knew that everybody in my life was taken care of," Olczyk said. However, as the grueling treatments wore on, he felt beat down. "I gained 50 pounds from the steroids, I had no color in my skin, my hair looked like bacon strips," Olczyk remembered. "It tested my will to live and broke me down; I wanted the Cliff Notes version of the disease but there is no short way through cancer."



#### ILLINOIS REP. MIKE QUIGLEY

Spoke on the House floor and used Eddie's story to emphasize the need for earlier screenings and continued research to find a cure.

February 2018

#### Feature **STORY**



66
FIGHT
for ME.

Fight for our kids and fight for the people who love you.

Diana's advice and plea to Eddie as side effects wore him down.

#### **EDDIE IS CURRENTLY**

A television commentator for the NHL on NBC and horse racing. He was selected as the NHL Hockey Fights Cancer Ambassador for 2019–2020.

Yet Olczyk's support system, especially his wife of 31 years—Diana, "his rock"—wouldn't let him give up so easily.

"I think all of us every now and then fall into a dark place where you go, 'woe is me,' but you've got to find the fight," she wrote in Olczyk's memoir *Beating the Odds: In Hockey and in Life (Triumph Press)*. "I was like, 'we're going through it this way. You've got to fight for me, for the kids, for the many people who love you and are counting on you. If you don't have the ability right now to do this for yourself, look around and do it for us."

The pep talk worked. According to Olczyk, "She gave me the greatest inspirational speech I ever got... and I've been in a few locker rooms. She helped wake me up—this was not me. We were going to do this. So, I got my hockey helmet back on and the mentality of remembering who I am. I took things day by day."

Starting with setting small goals, Olczyk refocused and set big and small milestones like sporting events and family weddings. Fighting the temptation to quit, he tapped into his family's strength as all of their eyes soon opened to the struggle cancer creates not only for the patient, but the caregiver.

"Caregivers may not be going through the physical part of being sick and facing treatment, but they're going through it psychologically," Olczyk said.

"I knew Diana would be alone and upstairs, feeling worried and scared. That's part of why Diana and I both want people to know how critical caregivers are now."

Caregiver needs are one of the many reasons Olczyk and his family are opening up.

66

#### I WAS MUCH STRONGER THAN I EVER KNEW.

I wanted people to know one day I woke up in a bad situation and the disease tested my will to live, but that I was not afraid to ask for help.

Eddie Olczyk



#### **OPEN BOOK**

"I've had hundreds of people say they've gone in and had a colonoscopy because of what happened to me," Olczyk said. "Even if I've kept one person from going through what I did, it's very gratifying."

As he reached big and small goals, like seeing the Cubs season start back and watching his son get married one year after his diagnosis, he felt the magnitude of his story. Hundreds of pieces of fan mail showed up to the Blackhawks' offices each week, along with requests from fellow patients or loved ones wanting to connect with him. For a guy who'd made it a point to help other people feel good about themselves, whether in the dressing room or the living room, he was receiving a dose of his own generous love. Co-commentator and longtime Blackhawks broadcaster, Pat Foley, told him:

"You've done so many things for so many people, partner. Now, it's time for a little 'getback.' I know there's been plenty of days when you need a little boost and a little energy and a little assistance, and we're all here to give it to you."

Thanks to the boosts and support, Olczyk reached one of his biggest goals: "cancer free."

#### **BEATING THE ODDS**

"Anything that I've done is more than an individual achievement; it's a family achievement," Olczyk said when reflecting over a life of beating the odds, ranging from sports drafts to late-stage colorectal cancer. He sees cancer as an experience that brought both changes and affirmation.

"Honestly, getting sick reassured me that I was in a really good place; I'm proud and lucky for that," Olczyk said. "The most important people in my life knew how I felt about them before cancer, and I continue to tell them. I am at peace. Nowadays, I tell people who hear my story that I hope they laugh and love a little bit more after reading what happened to me."

Starting in Chicago and going beyond, Olczyk's story is inspiring many survivors to keep on going and resilient loved ones to continue rallying.



## **CLINICAL TRIALS** in the face of

The global pandemic did more than shut down our cities, cancel our events, and strip our shelves of toilet paper.

It also impacted clinical trials. Here's what Dr. Scott Kopetz, the gastroenterology medical chair of oncology at MD Anderson Center, and Fight CRC board member Dr. Richard Goldberg, executive committee member of the Alliance for Clinical Trials, said.

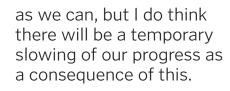


How has the pandemic impacted clinical trials?



DR. GOLDBERG: On a conference call with the National Cancer Institute (NCI), they emphasized the number one goal is eradicating and optimizing treatment, but their

observation is clinical trial renewal dropped dramatically. At the Alliance for Clinical Trials, we are keeping our clinical trials open and liberalizing criteria of when treatments need to occur, meaning people have a few extra days to get treatments. Some trials at the NCI that are not focused on survival outcomes are on hold, like quality of life research, and other things. But many trials continue to be open for accrual, especially in circumstances where we know protocol treatments save lives and when patients need access to novel therapeutics because there's no alternative. We're trying to enroll patients as much





**DR. KOPETZ:** At many clinical trial sites, there's a reticence to enroll patients in new studies. Some centers fully shut down across the board and both basic and clinical research was halted. In addition to local and national centers, some sponsors (pharmaceutical







DR. RICHARD GOLDBERG M.D, Board Member



DR. SCOTT KOPETZ M.D., Ph.D., FACP, Early Age Onset Working Group Member

#### Clinical Trials SPOTLIGHT





### Watch Dr. Kopetz

Watch our entire chat with Dr. Kopetz

companies) issued blanket statements to halt trials.



## What should patients do?



**DR. KOPETZ:** It's heartening to see the community come together and recognize the unique nature of this situation. Clinical research isn't always known for its flexibility, but we've seen investigators, treating centers, and sponsors recognize the most important thing is the best interest of the patient. Some trials have adapted by waiving visits, shipping drugs, and foregoing extra research tests which would have normally been done.

Oncologists are balancing the intensity of therapy with increased risk.



DR. GOLDBERG: I'd say to patients on a trial to try as best as they can to maintain the protocol they signed up for so we don't lose the learning they can provide for both the benefit of themselves and other patients.



What is your encouragement to patients?



**DR. KOPETZ:** It can be really scary and cause anxiety to change your treatment plan. I hope patients know this will pass. The welloiled health care system you're used to has been turned upside down and is undergoing a lot of disruption. But we will get back to normalcy. Patients must trust the oncologist, and although their recommendations may provoke anxiety, remember they're trying to find what's best.

Get more information about COVID-19 and Colorectal Cancer at fighterc.org/coronavirus and watch our talk with Dr. Goldberg on page 20.

**CLINICAL TRIALS** Finder



One of Dr. Gray's first tweets of 2020 was a photo of him smiling alongside a patient.

hot candidly on a mobile phone following a colonoscopy, it was a moment most would consider private. Vulnerable. But for Dr. Gray's patient, it was a moment for advocacy.

In a world drenched in patient privacy acts, Dr. Gray could have chosen to save the photo and not post it. But with his patient's permission and insistence, he tweeted it. It was a photo his group of more than 4,000 followers enjoyed.

"Social media matters for my patients and the broader health care community. It helps them find reliable, clinical, and publichealth related information amidst the sea of misinformation," said Dr. Gray. "And, it helps me stay abreast of innovations in science and groundbreaking research. I network with like-minded individuals and organizations

across the world on social media. It lets me share my thoughts, research, and achievements with those who may not otherwise receive them but would like to."

While social media may be one way

Dr. Gray stays engaged with both patients and fellow providers, it's also one of the many reasons he's one of the youngest, most respected doctors adding to the conversation about colorectal cancer.

#### **Big Footsteps**

Watching his father practice internal medicine in Baltimore, Maryland's inner city inspired Dr. Gray to follow in his father's footsteps and become a medical doctor. "I was in awe of him and the impact he had on people's lives in time of health and illness," Dr. Gray reflected.

Darrell Gray, II, MD, MPH, FACG

Following

Patient: \*pre-procedure\* Hey doc. It's good to see you, but are you old enough to do this? It's my 1st colonoscopy.

Patient: \*post-colonoscopy\* Can I request you when I need to come back? Also, can I take a picture with you?

Me: 8 Can I share it?

Patient: Send it everywhere.



12:06 PM - Jan 9, 2020

"The rapport he had with people from all walks of life, and the love he exhibited in what he did daily, was inspirational. My father was the spark that blossomed into a love for science and passion for patient care."

Following high school, an already-ambitious Dr. Gray enrolled at Morehouse College in Atlanta, Georgia, the alma mater of several other accomplished men such as Martin Luther King, Jr. For medical school, he chose Howard University College in Washington, D.C., an experience that laid a foundation for his work and achievements. As an aspiring cardiologist, he'd

planned to devote his medical career to studying the heart until mentorship from several gastroenterologists awakened his passion and calling in gastroenterology.

He completed a residency in Internal Medicine at Duke University Medical Center, a gastroenterology fellowship at Washington University in St. Louis, Missouri, and a Master's of Public Health at Harvard T. H. Chan School of Public Health. Today, Dr. Gray serves in many roles at Ohio State University **Comprehensive Cancer Center** in Cleveland, Ohio: an assistant professor of medicine; director of community engagement and equity in digestive health; the medical director of endoscopy and gastroenterology services at University Hospital East; and deputy director at the Center for Cancer Health Equity.

Balancing a full plate, Dr. Gray is driven by both passion and calling.

#### **Conversation Starter**

If you search for Dr. Gray's name online, you'll quickly find a growing list of awards and recognitions. Not yet 40 years old, he's often found on lists of top doctors and rising stars. When asked which awards mean the most to him, he said the Columbus CEO Practitioner of the Year, Medical Mutual Pillar Award–Philanthropist of

the Year, and American College of Gastroenterology SCOPY MVP Award.

Why these three? Because his family was with him when he received them.

Behind the caring doctor and passionate researcher is a family man and a conversation catalizer. In November 2017, he joined colleagues and friends across the nation to start the #blackmeninmedicine hashtag.

To describe the campaign, Dr. Gray said:

"As there are less black men entering and matriculating through medical school than in 1978, and as we know that diversity saves lives, our goals with this social media campaign are to: provide positive role models of black men in medicine; highlight achievements of black male physicians and those aspiring to a career in medicine; inspire black men to pursue careers in medicine;

Continues to PAGE 18

get to know construction of the construction o

**born & raised**BALTIMORE, MARYLAND

walk-up song

I probably wouldn't choose a recognized song and would instead use a custom beat from my friend Reudel Christopher (@16BitSpit on Instagram)

family

Married to Brittney and has three kids: Harper (5), Ella (3), and Noah (1). The rest of his family is in Baltimore, Maryland.

"Shout out to my parents, sister, brother-in law, nephews, aunts, uncles, and cousins!"

#### Caregiver FEATURE

Continued from PAGE 17

provide support, mentoring, and sponsorship of women of color in medicine who face challenges at the intersection of gender and race; speak up when we witness microaggressions, sexual harassment, or harmful bias and discrimination; and ensure a safe and inclusive educational, training, and working environment for all."

Today, the hashtag has received worldwide adoption.

#### **Relentless Champion**

"Dr. Gray is very easy to talk to. He listens to me patiently, answers my questions, gives explanations and treatment options; his comments are helpful and reassuring," said one of the many online reviews posted by his patients. As a provider, he's found a key to quality patient care: listening. As a medical provider, Dr. Gray may be young but he's leading the way in showing how to best support patients and provide patient care.

Because he's passionate about supporting all colorectal cancer patients, Dr. Gray recently joined Fight Colorectal Cancer's Medical Advisory Board, a small group of 30 distinguished oncologists, gastroenterologists, nurses, and researchers who ensure the information Fight CRC presents to patients is accurate and credible.

"Dr. Gray was on our radar as a thought leader in health care access and health equity based on his social media presence and respect amongst our top trusted medical advisors over the last several years," said Andrea (Andi) Dwyer, Director, Colorado Cancer Screening Program (CCSP) at the University of Colorado Cancer Center who is an advisor to Fight CRC. "When Dr. Gray reached out to Fight CRC for collaborative research, it was clear our perspectives and goals aligned. We are stronger together and

we are thrilled to have Dr. Gray join our team."

Dr. Gray will help ensure patients are well-informed about screening and treatment options, and communicating the latest data.

"It was a natural fit,"

Dr. Gray said. "I've been
partnering with Fight CRC
for years. This role provides
another touchpoint for
changing the narrative of
colorectal cancer in our
nation and working with an
amazing group of volunteers,
survivors, researchers, and
advocates to do so."

Sometimes relentless champions are survivors and caregivers fighting colorectal cancer together. But other times, they're the helpers—the nurses, researchers, and medical providers like Dr. Gray—who are working to prevent cases, support patients, uncover cures, and champion hope.



who do you fight for?

My faith, family, friends, and the patients and communities I serve.

#### FIGHT TOGETHER!

Here are a handful of resources that can help you stay connected to others and not fight alone.



## Sexual Intimacy

WATCH the WEBINAR

Sexual health is an important topic for many cancer patients and survivors.

Dr. Sharon Bober,
Founding Director of the
Sexual Health Program at
Dana-Farber, discusses
how to navigate a variety
of sexual health issues
that often come up for
colorectal cancer patients
and survivors.



#### JOIN our COMMUNITY at INSPIRE!

Inspire is a safe, privacyprotected place where you can connect with people who share your health concerns, obtain support, and find information about colorectal cancer.



#### **Talking to Kids about Cancer**

Leslie Welch, MS CCLS, Childhood Development Specialist, shares important information and tips about how to talk to your kids about your cancer diagnosis.

Topics covered include: common emotional reactions kids experience when a parent has cancer; how to discuss treatment and side effects; where to seek additional support; and more.

WATCH the WEBINAR



#### **FACEBOOK GROUP FOR ADVOCATES**

This group serves colorectal cancer survivors, caregivers, and others touched by the disease. We use this group as a way to provide updates to advocates, engage advocates to take action, and encourage discussion about policies that affect colorectal cancer research and screening.

JOIN Our FACEBOOK GROUP



#### **BULK UP!**

Looking for free, credible, medically-reviewed resources to distribute to your cancer center or support group? Look no further! Request bundles of Beyond Blue, Mini Magazines, Awareness Materials and more. Browse our online catalog or email <code>estore@fightcrc.org</code>.

**SHOP** the **COLLECTION** 

## COVID-19 & Colorectal Cancer



## We know 2020 hasn't looked anything like what most of us expected.

The fight against colorectal cancer is not easy, and the coronavirus health crisis has only added to patients' challenges and concerns. Nobody fights alone at Fight CRC, which is why our community rallied to provide patients with the latest information, practical support, expert advice, and activities that bring our community together in isolating times.

As we all continue to seek out a new normal, we hope you find these health and wellness resources helpful. Fight CRC is proud to be here for you during such a critical time for the colorectal cancer community.

#### Your Questions—Answered!

In a Fight CRC Facebook Live, Dr. Richard Goldberg addresses patient questions arising out of COVID-19 and covers immunosuppression, advice for newly diagnosed patients, worries about on-hold screenings and delayed treatments, and the impact of the virus on clinical trials.

WATCH the Q&A

#### Resource Line

Fight CRC's partnership with the Cancer Support
Community hotline has temporarily extended its
hours during the crisis, and staff is prepared to answer
questions about coronavirus and coping with social isolation.
This is a free call line available in English and Spanish, and it offers
translation services for more than 200 languages.

Live assistance is available from 9 a.m.-9 p.m. EST Monday-Friday, and 9 a.m.-5 p.m. EST Saturday & Sunday.

Toll-Free Line: 1-877-427-2111

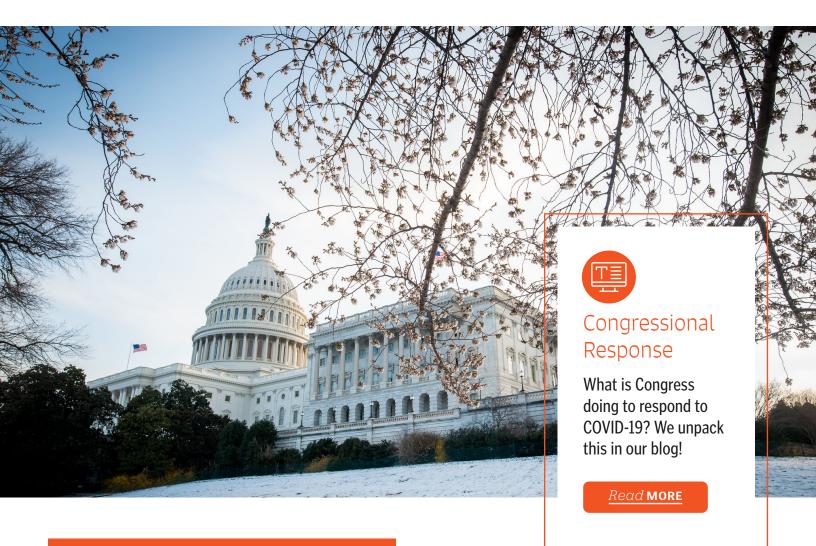


Join us for a digital series featuring an expert in a new wellness topic each week.



#### Cook with Ann

Cook for your Life founder Ann Ogden Gaffney makes two quick recipes with kale.





#### Hike with Brian

Brian Threlkeld, colorectal cancer survivor and Fight CRC's Climb Manager, shares his tips for hiking while maintaining social distance.

Virtual CLIMB REGISTRATION



#### Meditate with Andrea

Andrea Lee, BSN, RN, a mindfulness and mindset coach for Mindful Cube Consulting, guides us through a meditation.



How can you stay connected and show support to colorectal cancer survivors and caregivers from both near and far away?

## We asked our community. Here's what they said!





Host a virtual dinner party with friends! Cook for Your Life has some great healthy recipes that would be good for patients to try!

works well on every phone.

**CARRIE GIBSON** 

@crcgibsoneffect ©

**ELSA &** 

Caregivers

#### **SHARYN WORRALL, MPH**

Senior Manager of Education and Research @SharynFCRC >





Pick up or drop off kids at school or extracurriculars. Offer to pick up prescriptions or items from the store. Offer rides to appointments. My brotherin-law paid for cleaning service during treatment.

#### **CAROL GSTOHL**

Friend of CRC patient & Breast Cancer survivor @cgstohl

Communicate, call, pop in for a visit if that's possible, send a message. You don't have to say anything. Just the mere fact you are thinking of them and that you are there for them matters.

#### **CHARLOTTE JACKSON**

Caregiver @CJMEDITECHInt >



Act. Words can be difficult to find, but actions speak. Be their advocate. Accompany them to the doctor. Be that person who coordinates meals and services. Buy a gift or a card. Be there. Do something.

#### RICK BOULAY, M.D.

Medical professional @journeycancer 🔰



Offer to do specific things, such as cook a meal or offer a ride. We often are so overwhelmed by treatment, we have a hard time articulating what we need.

#### **CHRISTY LORIO**

Stage IV survivor @christylorio 🔰



Show up without saying "What can I do?" We probably will say, "I'm good," but just do it. Even if we're labeled terminal, we are still alive and living.

#### JENNIFER JANNETTE

Stage IV survivor @JenniferJanne10



Try making connections outside of your normal go-to ways. I know I'm personally feeling a bit overwhelmed by social media these days, so I am trying not to be online as much. Snail mail is still a fun way to send goofy gifts and messages to loved ones.

#### **ANDREW WORTMANN**

Community **Engagement Manager** @FightCRCAndrew



I ask people to help take pressure off my husband. Bring meals, sit with me so he can leave, buy Walmart gift cards so he can get groceries.

#### **SHIRAY BERRY**

Stage IV survivor @BerryShiray 🔰



When possible, do something "normal" with us. We all need breaks from routine, and for patients, the appointment/test/ treatment routine saps the spirit. Help us remember we are a "human being" rather than just a "cancer patient."

#### **STEVE SCHWARZE**

Stage IV survivor @EnvRhet 🔰



- ★ **34** states represented along with the **District** of Columbia and **Puerto Rico**
- **★ 4,056** emails sent to Congress
- ★ 561 individual playbacks and 447 viewers of the live stream
- **EVERY** Member of Congress was emailed



#### 2020 Virtual Call-on Congress

Fight Colorectal Cancer's Call-on Congress is an annual advocacy event where we bring advocates from across the country to Washington, D.C. for a three-day event each March. Patients, family members, and advocates gather to hear from leaders in the colorectal cancer community about the latest in research, treatment, and prevention efforts.

#### **WE NEVER GIVE UP**

In January 2020, we began monitoring growing concern that the spread of coronavirus (COVID-19) would force the cancellation of events across the globe—Call-on Congress among them. By early March, we made the proactive and responsible decision for the health and wellbeing of our attendees to cancel the in-person event. Fight CRC was one of the first organizations to transform a scheduled in-person event to a successful virtual one.

#### SHOWING UP

All of our scheduled speakers were committed to bringing our program into the homes of hundreds of people. As a result, we had our largest audience for Call-on Congress to date.

#### Continued from PAGE 8

alongside curative treatment. Anyone dealing with stress or symptoms due to the cancer diagnosis, or from treatment side effects, should seek a referral to palliative care.

Most cancer treatment centers have palliative care teams on-site or teams affiliated with the center. Palliative care is available in hospitals, outpatient settings. and sometimes at home. It's covered by medical insurance, including Medicare, the same as other specialists.

#### **IS PALLIATIVE CARE RIGHT FOR YOU?**



#### **TAKE A SHORT QUIZ**

to see if now is the time. to request a referral to palliative care and check what's available in your area by searching the Provider Directory at GetPalliativeCare.org.

TAKE the QUIZ



Palliative care is involved as long as you need.

Some patients see palliative care doctors and teams frequently, while others only see them when situations arise that their primary doctor isn't managing. So, if you have significant chemotherapyrelated symptoms that resolve when treatment ends, you may no longer need to see the palliative care doctor or team. Or, in the case of a patient with advanced disease who may undergo multiple rounds of treatment for an indefinite period, the palliative care team is there to provide help and support throughout the course of the patient's journey. It's based on your needs and you are always in control.



Palliative care helps your family.

Watching and caring for a loved one who is going through the cancer journey is difficult. Caregivers also suffer a great deal of emotional stress and struggle with their own self-care when they are caring for loved ones. The palliative care team is ready and available to support loved ones by providing a safe space to discuss concerns. This also includes

answering questions about how to anticipate possible symptoms and side effects, and what to do should something happen.

We place a lot of importance on caregiver stress because it's well known that patients do better when their support system is intact.



Palliative care works with your medical team.

The palliative care team shares all information with your other medical providers. They also work to ensure that everyone on your medical team oncologist, surgeon, radiologist, nurses, and social workers—is on the same page. They track your goals of care, how you respond to treatment, and the need for changes to make the treatment process as manageable as possible.

Dr. Martins-Welch specializes in palliative care in the outpatient setting.

She focuses on global symptom management for patients with advanced illness, working collaboratively with various specialists to provide patients the most comprehensive care. Dr. Martins-Welch has a particular interest in studying the effects of early palliative care for people living with cancer.

#### Get Involved FIGHT CRC EVENTS

#### **PRESIDENT**

#### **Anjee Davis, MPPA**

"While the coronavirus pandemic ravaged the world earlier this year, Fight CRC knew thousands were still being diagnosed with colorectal cancer and required support to fight the disease.

So we pushed forward by supporting our community with coronavirus (COVID-19) support, but also continuing to provide valuable resources to those diagnosed with colorectal cancer.

We also wanted to hear from our community. Fight CRC hosted focus groups and surveyed patients and caregivers to learn more about their concerns and challenges during this unprecedented time.

No matter what is happening in the country, colorectal cancer doesn't stop. It will still be diagnosed at an alarming rate among younger adults and the research into why only increases in urgency. The need for legislation to support patients and make screening accessible to all Americans does not slow down and, virus or not, newly diagnosed Americans will still seek out resources to inform urgent treatment decisions.

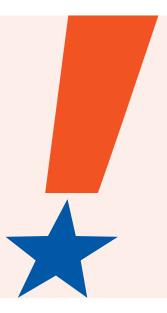
That is why Fight CRC always pushes forward. Relentlessly."



FOLLOW ANJEE!

@anieedavis





#### New to the Fight CRC Board

Earlier this year, Fight CRC welcomed to our board Dr. Richard Goldberg, international leader in gastrointestinal cancer treatment and research. We also welcomed attorney for the Illinois Fifth District Appellate Court, Joanna Haydon, who also is a Top 10 Fundraiser for Pedal the Cause, an annual charity cycling event that raises money for cancer research at Siteman Cancer Center in St. Louis.

**MEET** the TEAM



\* ON \* **CONGRESS** 

#### **CALL-ON CONGRESS GOES VIRTUAL!**

For the first time ever, Fight CRC took Call-on Congress online due to the coronavirus (COVID-19) pandemic. Read more about the event and its success on page 24, and you can watch the livestream back at CallonCongress.org.

WATCH the LIVESTREAM



**REGISTER TODAY** 

#### **CLIMB FOR A CURE FROM HOME**

Fight CRC's fifth annual Climb for a Cure is going virtual! We're disappointed to have to postpone the physical Climb in Squaw Valley, but we're excited to get climbers involved from home.

This year, our goal is to take 1 million cumulative steps to represent 1 million colon and rectal cancer survivors. Join us as we share tips on getting outside safely during COVID-19, tips on building strength for hiking, and tips on what to bring on a day out in nature.

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

















#### **Fight CRC Advocate Turns Staff** Member!

Stage IV survivor **Scott Wilson ioined** Fight CRC as its Mission Champion, Vice President.

Scott is an experienced business leader with more than twenty years of experience in communications, marketing, and regulatory affairs, mostly with Molson Coors Brewing Company. Scott is also a colorectal cancer survivor driven to change the future of this disease.

#### **FOLLOW SCOTT!**

@fight\_crc







## HONORING Someone SPECIAL

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

To ensure nobody fights alone, their loved ones have made donations in their honor. Donations to Fight CRC are a thoughtful way to recognize someone affected by colorectal cancer. Donations support year-round advocacy efforts, research, and patient education.

These individuals were honored by a donation to Fight CRC between 7/1/19 through 12/31/19.

Aida Dalia Lopez Al Steinz Alcede Roy Carter Alexander Brimm Alexander Chemerisov Alexandria Hite Ali Ismael Ali Alisa Cancino Andi Dunn Andrew Somora Andrew Weishar Andy Giusti Andy Schoolcraft Andy Tiefenthal Ann Sullivan Anton Loubser Benjamin Mueller Betty DiMaria Bill Fischer
Bill Hinckley
Bill Maxwell
Bill Salser
Bob &
Marlene Ceragno
Bob Dunn
Bobby Ryder
Bonnie Peska

**Brendan Davis Brett Hardecopf** Brian Gonda Brian Pruitt Brian Threlkeld Britt Ochoa Calogero DiMaggio Carmen 'Slim' Sharp Chad Johnson Charles William Michel Cheryl Garrett Chip Moore Chris Crawford Chris Ganser Chris Taiani Christine Niemi Christopher Crawford Dana Rye Daniel Dunn

Daniel Gaskill David Bruce Jackson David Burnett David R. McKenzie David Scarborough Debbie Wierum Deborah L. (Barnett) Koetter Deborah Sproule Debra Blemker Diane Kramer Diane Szczepaniak Diego Davis-Olegario Earl Casterline Ed Washington Edward John McCollough Edward L. Anderson Edwin Waldo Emerson Fleanor North





## We often receive donations in honor of those we've lost in the fight.

Many times, this is "in lieu of flowers," and, from time to time, Fight CRC also receives legacy gifts from family estates. Both are vital to continuing the important work of Fight CRC. Recently, the family estate of Kathryn West honored Fight CRC with a large gift. As our founder Nancy Roach remembers, "Kathryn's focus was always on patients and what they needed to make decisions." We're honored that she chose to continue her dedication to patients through this gift.

"A life dedicated to helping those with cancer continues through gifting more than \$700K to Fight Colorectal Cancer. Kathryn helped so many through direct patient care and indirectly through knowledge and education sharing. Whether it was helping you find a clinical trial or encouraging you to advocate for your needs, her legacy continues through the amazing work of Fight Colorectal Cancer whose key tenets and mission perfectly align with Kathryn's—how she lived her life and continues to give to all of us, even today."

Jimmy Doss, a friend of Kathryn West

#### Memorial **DONATIONS**

Elizabeth (Beth) Heide Elizabeth McAllister Eric Todd **Ethan Patrick Twersky** Fr Al Lauer Frank Hankin Freida Waller **Ganser Family** Geoff Wolf George Means George Velasco Gerald Green Gloria Kalka Gracie Howells Hartland John Conners Hausmann Family Heather Schiller Heidi Helen Tepper Jackie & Al Holmes Jade Hardecopf & Family Jake & Ben Johnson James Smarowsky Jan Scott IR Jean Krsak Jeff Taylor Jeffery Marek Jelena Tompkins Jenna Detko Jennifer Holcomb Jerome Villavecchia Jesse Burnette

Jim (Bubba) Goessling Jim Gilbreath Jimmy Wayne McNair Joe Smith Joel Paper John 'The Hammer' Christian John Doherty John Holl John Javenkoski John MacLeod John Paragallo John Sweet Ionathan Ahuatzi Onofre Jonathon Lawlor Josien Doornink Julienne Gede Edwards Kacey Cutri Kalief Robinson-Byrd Karl Judson Kathy Oliver Ken Zuroski Kenneth Bennett Kia Deveaux Kirk Strenger Kirsten Howells Lam Nguyen LaVerne J. Francisco Lawrence Goldberg Lewis Moore Linda Brune Linda Granville **Lindsay Soloff** Lisa Johnson

MJ Margaret Clerico Margaret Reed Finch Marquerite H. Martin Marilyn Rousso Mark & Marijane Mitock Mark Eichelberger Mark Gottman Marvin R. Emerson Mary Carey Mary Hightower Walker Mary Job Mary Lanz Mary Lee Myers Mary Salvi Mary Sandra Berning Wendell Matt Moore Matthew Gunnels Melvin R. Bernard-Toledano Merlene Knuchell Michael Arclise Michael Borucki Michael Mancini Michael Yie Michelle Insco Michelle Von Feldt Mike Mule Mike Robinson Miriam Silverman Nancy Alper Nancy M. Eastman Nelson Errie Gibson Nona Li

Norma K. Louft Ocella Denise Fehrenbach P. Sean Donovan Patricia Shelton Patrick Moote Patrick Oldani Patrick Sheehan Patrick Wohlwend Patsy Huggins Petzold Patti Martins Patty Wood Peg Myrick Randall Cox Rav Beckler Rayna Freedman Rebecca Gleason Regina **Huffman Eubanks** Rev. Dr. William F. Dean Rob & Andrea Kramer Robert Allred Robert Edman Robert John Fields Robert Michelson Robin Tyler Robyn Schmid Tiffie Rocco DiBartolo Ronald C. Diltz Ronald Dilts Rose Hausmann Rosetta Ragusa Salvatore Recupero Sandra Lesh Satyanarayan Vishnubhakat

Scott Zilverbera Shannon Stockton Shelli Suchanek Shirley Mongold Sigurd Rinde Son of Robert Lee Stanley D. Hyman Steve Ashcroft Steve Baker Steve Walters Steven Plice Steven Walters Stuart Schwartz Summer Maune Suzanne Yavor Tania Harris Teri Greige Thomas Martinchek Thomas Mitchell **Thomas Waters** Tim Ruediger Tom Kammer Ton Jurriens Tracy Mead Umer Iftikhar Vernon R. Bock Jr. Vivian Freid Allen Walter Hickman Walter Richie Wayne Jones Wayne McNair Wendy Weisman Whittington William R. Eastman Sr. William Stout Willie & Maggie May Brown



Jessica Martin

**TO ENSURE** your loved one's name is in our fall issue, visit give.fightcrc.org.

Luke Perry

MAKE A Donation

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

Scott Oomen



Yusof Ganji



# FLGHT COLORECTAL CANCER EDUCATION!

IF YOU'VE BEEN DIAGNOSED WITH COLORECTAL cancer, you'll want to start treatment right away. But wait to make sure you have all the information you need! Knowing your colorectal cancer biomarkers before you start can help your doctor identify the best treatment for YOUR cancer.

Learn more. Download Fight CRC's free Biomarker Mini Magazine at **FightCRC.org/Biomarked.** 



Get your free copy at FightCRC.org/Biomarked