

BEYOND BLUE

A Biannual Update For Those In The Fight Against Colorectal Cancer



THE NEW JONAS WAY

HOW TO MEDITATE • LINDA'S STORY • EMBRACING THE OSTOMY
CHANGING THE FUTURE • MISFORTUNE VS. INJUSTICE

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Dear Advocate,

March, Colorectal Cancer Awareness Month, is a catalyst for our activities and this year it served as a uniting force both nationally and globally. We convened leaders, experts and survivors from around the world to discuss patient care, early-onset colorectal cancer, advocacy and the future path for colorectal cancer research.

On the advocacy front, three days after our lobby day in Washington, D.C., we saw the president approve \$3 billion in research funding (check out page 17 for details)! We convened discussions on Capitol Hill, but we also took action.

We often hear from patients and experts that the colorectal cancer environment is changing. To keep up, we have to come together and broaden what we do. This goes for patients, caregivers, medical professionals and even Congress.

Whether it's learning to be mindful (see page 4), adopting a different mindset like survivor Kevin Jonas, Sr. (page 10), living with an ostomy (page 8) or using our experiences to impact policy and influence others (page 18), embracing change and new ways of thinking is something we all inevitably must do.

I hope you'll see in this issue of Beyond Blue our commitment to the power of stories. Personal discussions and connections strengthen and encourage us as a community.

Our discussions are evolving and we are embracing and anticipating the changes ahead. And, we are listening. I'm so proud of our Fight CRC advocates who show the world there is hope, strength and courage in light of life's uncontrollable ebbs and flows. There is power in accepting, adapting and embracing change—power that strengthens our fight.



 @ANJEEDAVIS

Anjee Davis

Anjee Davis, MPPA
PRESIDENT

ABOUT FIGHT COLORECTAL CANCER



VISION

We envision victory over colon and rectal cancers.

MISSION

We raise our voice to empower and activate a community of patients, fighters and champions to push for better policies and to support research, education and awareness for all those touched by this disease.

SAVE THE DATE

Climb for a Cure

JULY 16 2018

Get moving! Join other adventurous survivors, caregivers and loved ones fighting colorectal cancer to build camaraderie, raise funds and inspire others. Join the Virtual Hike!

FightCRC.org/Climb

August Recess Challenge

AUGUST 2018

Each year, Fight CRC hosts an August Recess Challenge to get advocates involved in advocacy from home. The August Recess Challenge is an annual grassroots advocacy campaign with weekly challenges like meeting with your members of Congress, calling your representatives or engaging with them on social media. Make your voice heard from home!

FightCRC.org/AugustRecess



13th Annual Call-on Congress

MARCH 17-19, 2019

Learn how to make YOUR story the one your elected official thinks of when voting on healthcare policy and research funding. Get details and register at CallonCongress.org.

CONNECT WITH US ON SOCIAL!



@FIGHTCRC

HOW TO GET INVOLVED

1. Visit FightCRC.org
2. Fill out the "Get Updates" form or sign up to volunteer!
3. We will be in touch!



EVEN MORE LOCAL AND NATIONAL EVENTS ARE HAPPENING NEAR YOU! FIND MORE DETAILS AT FIGHTCRC.ORG/EVENTS



HOW TO MEDITATE

BY ANDREA LEE, BSN, RN

Cancer is a life-threatening, life-changing experience. Meditation and mindfulness are techniques that may help survivors, caregivers and loved ones cope. At the 12th annual Call-on Congress, Andrea Lee, BSN, RN, Oncology Program Manager at Methodist Dallas Medical Center, led a breakout session on how to meditate. Studies show meditation can bring major benefits including reduced stress, reduced pain, improved sleep and more.

To get more tips from Andrea about meditation and mindfulness, visit FightCRC.org/Mindfulness. The following is a Q&A interview with her and several tips for getting started.

Q1: Is there a right and wrong way to meditate?

It can be difficult to discern if what I am doing while sitting with my eyes closed is the same as what someone else is doing when they are sitting with their eyes closed. *How do I know if I'm doing it right?* is a very common question.

Many people think meditation means they have to stop all thoughts from entering their mind. That is impossible—humans are thinking beings. Ever notice how when you try to stop thinking about something you think about it more? That's because whatever we resist grows. If, when we sit down to meditate, a thought pops into our mind, and we think "I shouldn't think that" then those thoughts are more likely to become stronger and demand our attention.

However, if we turn towards the thought and non-judgmentally and compassionately acknowledge its presence, it tends to naturally dissipate. This is how we learn to meditate. The process of 1) recognizing when a thought has entered the mind, 2) acknowledging the content of it, 3) letting it go and recentering on the breath is how we rewire the structure of our brain. Even if you have to witness a thought and redirect back to the breath 100 times during a 10-minute meditation, that is okay.

The wrong way to meditate would be to block thoughts or follow thoughts as they arise. If left unattended to, the mind will follow one thought to the next until it has taken someone down a rabbit hole of fear, anxiety and delusion. If we are not careful we can even convince ourselves these thoughts are true! Human thinking is embedded with biases, such as a negativity bias that draws our attention toward threat of danger, so most often these catastrophic thoughts are not true and should not be followed. What most of us are trained to do is push the nagging thought away. However, if I am resisting thoughts, pretty soon those thoughts will take over how I am feeling and I will feel a compulsion to get up from meditation practice. This is one reason why non-judgment and compassion are crucial attitudes of mindfulness—they allow us to observe a thought without identifying with it.

Meditation is like fitness.

We go to the gym or exercise our bodies so we feel physically fit. So, if our mind tells our body what to do (first I have the thought to go exercise before my body does what I tell it), we should treat meditation like mental fitness. Meditation, when formally practiced, literally carves grooves of neural networks in our brain that strengthen our ability to navigate the challenges of everyday life.

Q2: At what point do I know that meditation isn't working for me? What would I do if I know that I'm not gaining any benefit?

Your brain is a muscle, and just like any muscle, it grows stronger the more you use it. Mindfulness practice works if you use it, but the key is how to get yourself to do it. A good rule of thumb is that if you think you're too busy to meditate, you need to meditate twice as much. One should be patient with the process, for it takes repeated practice to notice the functional difference that results when those areas of the brain strengthened through meditation grow stronger. If someone trying to lose weight went to the gym for one week, what type of results would you expect they would see? They might feel better in their body, but would you expect to see much of a difference in their waistline? Probably not. The same is true for meditation. If you're just starting out, it's important to be realistic about your expectations. In the beginning you might feel calmer, and have an increased sense of presence or peace, but it will take repeated practice to begin to notice the significant changes in how you attend to everyday life. Meditation strengthens an area of your brain called the middle pre-frontal cortex. This area behind the forehead governs functions like insight, empathy, attuned communication, body awareness (what is happening inside the body), response flexibility (widening the gap between thought and action that allows us to clarify if an action we want to take is truly in line with our values), etc. MRI studies show that participants who practice mindfulness meditation have increased cortical thickening in these areas of the brain. Again, structure and function are related, so if you don't feel like you're benefiting from practice, my advice would be to seek a meditation teacher or guide of some sort who can help you refine your practice.



Andrea Lee, BSN, RN



Q3: What are some tools to help me get started? Are there any online apps or groups I can attend? Any tips for beginners?

Set realistic meditation goals. Research shows that even 10 minutes a day can begin to strengthen these areas of the brain that allow people to override their stress response and find more peace in life. Start with 10 minutes for one week, then 15 for the second week, and 20 for the third. It's so easy to convince ourselves we don't have time for meditation, but really it's the most important thing we could ever do. Remember that everyone battles that feeling, and the practice only works if you do it. Try making it easy for yourself to succeed and hard for yourself to fail. Humans are social creatures, so when attempting to form a new habit, having an accountability partner can be helpful. Even if you don't practice together, the act of being accountable to someone can help get it done. After a while, you will begin to notice the beneficial effects of meditation, and the behavior becomes self-reinforcing. The point at which new habits become self-reinforcing is the sweet spot for habit formation. Humans are pleasure-seeking, pain-avoiding mammals, so once we notice the reward for our behavior, we become intrinsically motivated to carry out the action and it becomes less effortful (habituated).

TIPS FOR BREAKING OUT OF A THINKING & FEELING LOOP:

- 1. Breathe into the feeling**
- 2. Label the thought or emotion**
- 3. Become aware of mental activity**
- 4. Practice self-compassion**
- 5. Reframe/reorient**
- 6. Choose differently**

I like to surround myself with little reminders as visual cues of how I want to think, feel and be. One sign I have next to my computer at work is a short list of things I want to remember in any given moment. This can be anything from who I want to be, or how I want to think/feel. I look at this list every day when I get to work and find that these short phrases come to mind when dealing with various situations that arise in my day:

- Become aware of bodily sensations
- Live in the present moment
- Embrace silence
- Get rid of toxic elements
- Relinquish the need for external approval
- Don't judge myself and don't judge others
- Replace fear-based thinking with love-based thinking

What is right for me might not be right for you, but affirmations work. Reinforce how you want to think, feel and be. Think thoughts about it. Think more about what you want and less about what you fear. It will be amazing how thinking and feelings change. Thinking and feelings drive action and decision making... I encourage you to experiment and see what you find.



KEEP READING!

TO GET MORE TIPS FROM ANDREA
ABOUT MEDITATION AND MINDFULNESS,
VISIT FIGHTCRC.ORG/MINDFULNESS

VISIT OUR FULL RESOURCE LIBRARY AT
FIGHTCRC.ORG/RESOURCES

TOP10LIST

How Fight CRC Research Advocates are Changing the Future of Colorectal Cancer

1 Curating the Late Stage MSS-CRC Trial Finder

This tool helps patients with late-stage microsatellite stable (MSS) colorectal cancer find clinical trials. Trained research advocates are behind the scenes reviewing trials that get posted to the finder, looking for trials with the highest potential for success and the lowest chance for failure.

TRIALFINDER.FIGHTCRC.ORG



“As an advocate for my son who was diagnosed with stage IV colon cancer in 2013, searching online databases was daunting. The existence of a trial finder like this opens the door to hope and improved treatment.”

—Lera Chitwood, Caregiver

2 Investing in Research

Recently, we funded a \$400,000 grant in partnership with the Cancer Research Institute (CRI) to Dr. Cindy Sears at Johns Hopkins University School of Medicine for her investigation into the role of the gut microbiome in colorectal cancer. Funding research helps advance the understanding of colorectal cancer and leads to improved treatment options.

3 Convening the Immunotherapy Workgroup

Researchers, clinicians and advocates meet twice per year to discuss the state of the science for CRC. In November ‘17, the workgroup’s manuscript: *A Blueprint to Advance Colorectal Cancer Immunotherapies* was published in the Journal of Cancer Immunology Research. This publication is guiding immunotherapy research and encourages universal MSI testing so we can better understand treatment options and patient outcomes.



“The immuno-oncology field is a complex, fast-moving, and exciting area of promise for more effective treatments, and the workgroup convened by Fight CRC and the CRI has brought together a team to ensure that patients’ needs are being met and addressed by the academic, pharmaceutical and research communities.”

—Chris Lieu, M.D., University of Colorado School of Medicine

4 Advocate-Expert Discussions

We engage in high-level discussions with experts in the field at conferences, meetings and national forums including the American Society of Clinical Oncology (ASCO), the American Cancer Society, the National Cancer Institute (NCI) Colon Task Force and other local and state task forces. This has led to collaborations between experts to develop solutions for reducing barriers to and increasing clinical trial enrollment.

5 Informing Cancer Programs

We’re participating in the development of new cancer programs, such as palliative care and survivorship care programs. Chris Ganser, a stage IV survivor and Fight CRC advocate, guided the development of support groups at his cancer center to help ensure patients would receive the best care available.

6 Raising Awareness

Fight CRC research advocates are well educated and up-to-date on evidence-based screening strategies relating to CRC prevention and recurrence. They’re committed to raising awareness about signs and symptoms and encouraging others to get screened.

7 Advocating for Federal Research Dollars

We advocate for federal research funding every year. Check out the BIG victory we recently experienced on page 17!



“Being a research advocate has given me the ‘power of knowing’—knowing how policies and alternative methods of treatment empower patients’ survivorship and knowing how to help others in their cancer journey.”

—Wenora Johnson, Stage III survivor

8 Infusing the Patient Perspective

Fight CRC research advocates sit on panels for the FDA, the Department of Defense and local institutional review boards (to name a few). Research advocates actively engage with clinicians and researchers, provide insight into clinical trial designs and review grant proposals. Having trained and trustworthy research advocates ensures the collective patient voice is being represented.

9 Sparking Critical Partnerships

Andrea (Andi) Dwyer and Dr. Chris Lieu spoke at the National Press Club alongside the National Comprehensive Cancer Network (NCCN) about partnerships between advocacy groups and academic centers. These kinds of partnerships can drive research initiatives. For example, our research advocates interfaced with academic partners and staff at the NCI to further the aim of biomarker testing being standard of care.

10 Contributing to Early Age Onset Research

We work with experts and leaders to thoroughly examine cases of early age onset colorectal cancer, including the impact of screening, early detection and causation. We are currently gathering case studies to inform the research and clinical care of early age onset survivors.



“We’re hearing growing concerns from survivors and advocates about both the emotional and physical toll early age onset colorectal cancer has on patients. It is an issue that needs additional research and an area we are dedicated to exploring.”

—Andrea (Andi) Dwyer, Director of Health Promotion



embracing THE OSTOMY

Receiving a colorectal cancer diagnosis means a variety of changes are bound to occur. For some, this could include an ostomy. While having an ostomy and wearing a pouch or ostomy bag is the result of a surgical procedure geared towards treating the cancer, living with a new “waste removal system” can be a challenge to embrace.

In fact, people with an ostomy often report body image and self-esteem issues, have a long list of questions related to maintenance and cleanliness. They report never-ending concerns over how an ostomy will affect their social life.

According to Joanna Burgess, BSN, RN, CWOCN, who has been living with an ostomy since childhood, “Learning to live and accept life with an ostomy is a personal journey. To help with the process of adapting, an ostomy mentor can be the key. An ostomy mentor is someone who has been through ostomy surgery and has learned that an ostomy changes, but does not limit one’s life. Ostomy mentors can be found through local United Ostomy Associations of America (UOAA) -affiliated support groups or online support groups. By spending time with someone who has already been through ostomy surgery, you will realize that you are not alone, and that life does move forward and can continue to include all the things that you loved prior to ostomy surgery.”

With the support of a care team, it's possible to adapt and embrace life with an ostomy. Whether you have a colostomy, ileostomy or J-pouch, life with a stoma can be full! Swimming, sex, plane travel... you can do it all. Many Fight CRC advocates are ostomates out there living their best life with an ostomy.



PHOTOGRAPHY
BY DOUG DALLMAN



DOUG DALLMAN IS PUTTING OSTOMY BAGS ON MONUMENTS ALL OVER THE WORLD AS HE TRAVELS.

I first started putting ostomy bags on statues to amuse myself. Kind of like a graffiti/guerrilla marketing campaign. I thought it was something highly irreverent and perhaps a stark reveal to non-ostomates that there are a lot of people who walk amongst them who have this condition. It was an in-your-face thing to raise awareness. And I think it's working. I'm seeing more and more ostomates on Instagram do the same thing. I hope it helps continue the conversation and connects other ostomates.

DOUG DALLMANN, #OSTOMYGRAFFITI
@PACNW TREKKER



STOMA: An opening created by surgery on the wall of your abdomen to collect waste

ILEOSTOMY: a stoma formed by bringing the end of the ileum out to the surface of the abdomen

COLOSTOMY: a stoma formed by bringing part of the colon out to the surface of the abdomen



SUZANNE DORE BLOGS ABOUT FASHION, TRAVEL AND LIFE WITH A STOMA.

What cancer tried to take away from me, my colostomy gave me back in bucket loads. I appreciate every single day I've been given extra. My life now, post stoma, is bigger, better and bolder than before I was diagnosed, there was no chance I'd waste a minute on negativity. I'm loving life, bag and all.

SUZANNE DORE, GLADRAGSANDBAGS.ORG
@SUZI1DORE



LISTEN TO THE "TABOO-TY" PODCAST
ABOUT LIFE WITH AN OSTOMY
FIGHTCRC.ORG/OSTOMY

A photograph of a man with dark hair and glasses, wearing a light blue button-down shirt. He is smiling and flexing his right bicep. The background is a bright, possibly beachside setting.

THE NEW JONAS WAY

PHOTOGRAPHY
BY TRAVIS HOWARD

BY DANIELLE RIPLEY-BURGESS

“

I LOOKED INTO CUTTING DAIRY, STOPPED DRINKING CAFFEINE AND RED BULL... BUT THE SYMPTOMS PERSISTED. I WAS A NERVOUS WRECK ABOUT GETTING MY COLONOSCOPY.

”

KEVIN JONAS, SR.
STAGE II SURVIVOR
Twitter @PAPAJONAS



Kevin keeping a smile while in the hospital.



The Jonas Brothers waiting for their dad to get out of surgery.

With a last name like Jonas, not to mention, several successful businesses and chart-topping sons, one of the last things Kevin Jonas, Sr., sometimes known as “Papa Jonas,” wanted to do was slow down for colorectal cancer screening.

The busyness of life gave him several excuses to push off his colonoscopy. A southern-style restaurant named after his grandmother, Nellie. Managing talent and up-and-coming artists. And then, there was the fear. And nervousness.

“I spent years chasing symptoms... stomach problems, heartburn, back pain, cramping during stress,” he said. “I looked into cutting dairy, stopped drinking caffeine and Red Bull... but the symptoms persisted. I was a nervous wreck about getting my colonoscopy.”

For years, Kevin ignored an internal voice that kept nudging him to see a doctor, claiming he was living the “Jonas Way”—pushing through difficulties and pain, bearing the discomfort to eventually overcome. And while the ideal was built on the backs of his hard-working family and led to years of resilience amongst much fame and success, it wasn’t helpful when it came to his digestive issues and cancer screening.

Kevin finally scheduled a colonoscopy two years after it was recommended when he turned 50 and soon he received the news: stage II colon cancer. While it was hard to take, he soon became grateful the cancer was caught at an early stage, when it’s highly treatable and curable.

“I don’t know what it would have been had I not gone in when I did—maybe stage III or IV,” he said.

Not only was he learning the world of fighting cancer between surgeries and chemotherapy, but he was discovering a new area of influence with a near-immediate impact.

“It’s amazing how many people have told me they’ve also put off their scopes and my story has caused them to go in. It’s had quite an impact so far and I’m hoping people hear my story and go get checked.”

A unique impact destined for a Jonas to make.



MUSICAL BEGINNINGS

The Jonas family has had many eyes and ears turn their way over the past several decades. When big news hits Kevin, his wife, Denise, or any of their four sons and their families: Kevin Jr., Joe, Nick or Frankie, it's likely to be printed in a magazine, discussed over airwaves or posted on social media.

But it wasn't always like that.

Kevin grew up in Belmont, North Carolina and was raised by a hard-working family who made their living working in cotton, like most other people around town. As a young child, he began to play music and developed a passion and calling for it. Music led him to a Dallas-based Bible college where in the registration line on the first day he met a fellow student named Denise. Instantly struck by her beauty and kindness, she was there to study sign language and become a missionary, the two married in 1985. Over the years Kevin worked as a pastor and their family moved from the Dallas area to New Jersey where they began their family.

As music continued to weave itself into the fabric of their family's life, Kevin didn't only see his sons pick up his same love of piano, guitar and vocals but he saw their immense talent and opportunity. Being so close to New York City, Kevin and Denise decided to let their sons audition for Broadway and like many stars can say—the rest is history. Their son Nick booked his first Broadway role at age 7 and began performing when he was 8. The three oldest boys formed a band later signed by Columbia Records - The Jonas Brothers - catching the attention of Disney and many of its fans.

As a family, they spent the majority of the years between 2005 and 2013 traveling the world, from all 50 U.S. states to nearly every major country on the globe.

"As a family, we worked together to achieve what my sons have done."

In 2013, the brothers decided to pursue solo careers and Kevin went back to being "dad" and now "grandpa" to two granddaughters. But in light of the career changes, songwriting sessions, globetrotting and Hollywood fame, the Jonas family always has, and still does, maintain an extreme closeness that's supporting one another through every twist and turn—including Kevin's colorectal cancer.

"When my boys heard the news they cancelled everything to be there for my surgery and they have been with me every step of the way."

In fact, having the boys' support is part of what made Kevin's fight with colorectal cancer a very public one.

"We knew the story was going to leak because there were rumors going around. I lost a lot of weight and people saw my sons at Memorial Sloan Kettering in New York City. We decided to control the message and share the news rather than have people speculate."

The family released the information about Kevin's diagnosis and as soon as it hit, not only did it make headlines around the world, it opened up Kevin's eyes to his new role as a cancer survivor.

"After I told my story, someone told me, 'Kevin, you've had a big impact already but this will make an even bigger impact on people's lives. It was a very emotional moment. That's when I owned it: I am a survivor."

“

**SAYING IT AND OWNING
THAT I AM A SURVIVOR WAS
A STRUGGLE FOR ME. BUT
IT'S AN IMPORTANT WORD.**

”

**KEVIN JONAS, SR.
STAGE II SURVIVOR**



Kevin Jonas, Sr. looking strong in the hospital.



CONNECT THE NEW JONAS WAY

SURVIVOR LIFE

While he's had an amazing support system and a team of doctors working to fight his disease, his experience has been anything but easy. While his prognosis was optimistic from the start, post-surgical complications leading to more surgeries and chemotherapy side effects, like neuropathy and fatigue, have made hospital stays and doctor's visits the norm. He continues to face surgeries and frequent scans to monitor any evidence of disease.

But with the ongoing hurdles he jumps through, being called a survivor means so much more.

"Saying it and owning that I am a survivor was a struggle for me. But it's an important word."

A word that's changing the lives of his family and anyone else who follows them. Because he's a first-degree relative for his boys, they're all encouraged to get screened earlier than age 50. And, he's hoping to make an impact on men like him who can relate to his story.

"I hope I'll impact guys like me—those dads who need to go in for their colonoscopy. I hope they'll take my example as an encouragement. If they get there early enough, it might even save their lives."

His story also nudged his wife, Denise, to get screened. As a supportive caregiver, she's walked side-by-side with him throughout his diagnosis to ensure he has everything he needs to get well. And now, she's joining him in his advocacy as they share their family's story in the hopes of seeing others avoid the path their lives took.

"There's nothing greater than helping stubborn guys and gals like me get screened," said Kevin.

Although it's been a difficult experience both physically and emotionally, the Jonas family is using what they've been given to help others, this time finding purpose not only in their passion but also their pain.

As he continues to embrace what it means to be a survivor, Kevin finds power in simply sharing his story, as it helps him embrace life's new normal.

"It is part of my healing to say something."

Today, Kevin and Denise agree there's a new "Jonas Way."

It still includes a strong family bond, a lot of grit and immense dedication and hard work. But it also includes taking care of yourself and listening to your body, especially if that means getting screened for colorectal cancer.



DID YOU SEE US IN PEOPLE MAGAZINE!?

Kevin's story and news about him becoming a Fight CRC national spokesman was featured in a March issue of People Magazine!

ODDY PREPARED

In 2014, David Jackson, also known as the Portland Trailblazer's DJ OG One, lit up the crowd that had flooded into Portland's Pioneer Square. As our first west coast One Million Strong event, we used anything and everything to draw attention to the heart of the city—an inflatable colon, a marching band, plastic butts, a flash mob and even acrobats. Local hospitals and healthcare groups came out with brochures, activities and information about colorectal cancer screening and prevention. As the day went on, David stood behind his turntables and helped us draw the crowd and broadcast our message: *"Don't wait! Get screened for colorectal cancer!"* Little did he know, three years later, the tables would be turned on him.

“
**EVERY MINUTE THAT
GOES BY, SOMEONE
UNINFORMED IS AT RISK.**
”

DJ OG ONE
STAGE III SURVIVOR

PHOTOGRAPHY
BY NAIM HASAN





In 2017, David turned 50 and during a doctor's appointment, he was encouraged to get a colonoscopy for colorectal cancer screening. He didn't feel sick, and he was uncomfortable with the idea of the test, "I didn't want a tube up my butt," but, he trusted his doctor of over 20 years and scheduled the procedure. Although spooked at first, it was easier than he expected and now, he's extremely glad he did it.

"I woke up from the colonoscopy and they said, 'Mr. Jackson, you have stage III rectal cancer.' I didn't know how to feel about it honestly—I was numb. I had no feeling outside of 'what's next?'"

David told only his wife for a few months while they developed a plan and learned the terminology of the disease. He went on to have surgery and treatment, which went smoothly at first yet brought several additional complications. Despite his setbacks, he continued to stay positive and let his community surround him. Working as a mentor to kids and their families in the Portland area for over 30 years, he quickly received a lot of support that helped him face the "why me" questions as well as the temptation to see cancer as punishment.

"It was weird to be on the receiving end of so much support, it was humbling. I didn't ask for it, but many people stepped up to wrap their arms around me. It's been amazing."

The support surrounding David fueled him to become even more vocal and open about his disease. The power of his platform was not lost on him, and as he's recovered, he's shared his story with the hopes of saving more lives and helping others from going through the same thing—particularly fellow African Americans.

"No one talks about this cancer - particularly African American men. We know it exists, but we don't talk about it. It's taboo. We don't talk about things having to do with our butts... but we need to."

If education and awareness takes David getting out there and being open about his story, that's what he's going to do. Whether he is turning the tables at the Blazer's game, mentoring in the Portland community or nationally advocating alongside Fight Colorectal Cancer, he's ready to do what he can to help and make others aware of this often silent killer.

"The One Million Strong event in Portland was the first time I was made aware of colorectal cancer. But it still didn't feel relevant to me, I didn't feel sick, and that's the mindset in our community. I want to help create more conversations."

How and where this community mentor and public figure will find ways to talk about colorectal cancer is still unfolding, but there's one important place he's gone to first: his family.

"After I was diagnosed, I found out other family members had dealt with, or were dealing with, cancer—including colorectal cancer. It was eye-opening... 'This runs in my family! Why didn't we have discussions about it?' I'm now having my sons and daughters get checked, and several of my other family members are too."

Whether at home, at the stadium or in the community, David is embracing the changes cancer has brought to his life. He's always been one for giving back and being involved in the community, and he views colorectal cancer as another way to help save a life and start a much-needed discussion.

"Once I became aware of the significance of this cancer I started asking, 'Why don't we have dialogue about this?' We talk about other things like reality TV. We want to save lives and discuss gun violence. But we don't talk about colorectal cancer. But my story is I wasn't sick. I was functioning and doing my thing. I felt fine... and all of the sudden my life changed."



45 OR 50?

After his diagnosis, David learned that screening for African Americans is recommended to begin at age 45. He is now avidly sharing the importance of screening with his family, friends and community.

CONNECT LINDA'S STORY

LINDA'S STORY



When Jerry Vandeveer lost his wife Linda to colon cancer, he became a man with a mission. Jerry has gained notoriety in his hometown for his colonoscopy awareness efforts, which include billboards featuring his late wife.

Jerry became inspired by Linda's fight and determination, and would share snippets of her battle on Facebook while she was still alive. People marveled at Linda's optimism and faith. Local Fort Wayne, Indiana, police and firefighters supported Linda by putting up "Pray for Linda" signs, and soon hundreds of people started following her story on social media.

Linda passed away in 2016, but not before making Jerry promise that he'd continue her wish of bringing awareness to colon cancer and colonoscopies. He's a self-proclaimed "colonoscopyholic," and he says that he could speak about colonoscopies forever.

"My Linda didn't get her colonoscopy at 50, and neither did I," says Jerry, "She would probably still be here if we had been better informed. I think we were both afraid of what we would find, and no one told us how easy the procedure actually is."

Jerry decided that the best way to honor Linda's wishes and memory was to bring awareness in a huge, spectacular way. Billboards were his first thought, since people frequently see them while driving, and he knew they would capture the attention of a larger audience. The billboards feature a photo of Linda and a call to action to get a colonoscopy.



BY ALEX HERNANDEZ

He wants people to stop fearing colonoscopies, and to realize screening and early detection are better than having to go through chemotherapy.

"At first I didn't know how I would even try to save lives, when my Linda had lost hers," admits Jerry. "But knowing that people have seen the billboards and are getting screened because of them reinforces my mission."

With messages such as "The prep for a colonoscopy beats the heck out of chemo!" and "One day of inconvenience could save your life," Jerry hopes those who see the billboards in his hometown will be inspired to get screened. So far, Jerry has paid for more than 20 billboards in his hometown, and dozens of people have contacted Jerry to let him know they've been screened or they're getting ready to get screened.

Jerry also rewards locals who get a colonoscopy with a leaded or stained glass window, which he refers to as "Badges of Honor and Courage." All people have to do is send him information about their colonoscopy, including name, date of procedure, name of doctor, and name of medical institution. Jerry gave 32 awards in 2017.

"People contact me and tell me they were afraid of getting screened, but that my Linda's billboards pushed them to make the right decision," says Jerry. "My Linda continues to save lives, and I think she'd be very proud to see what her story has done."

To learn more about Linda's story and Jerry's awareness efforts, go to the movement's Facebook page, "Colonoscopy, the Gift of Life."



COLONOSCOPY IS ONE WAY TO GET SCREENED FOR COLORECTAL CANCER, BUT THERE ARE SEVERAL OTHER NON-INVASIVE, TAKE-HOME TESTS AVAILABLE. KNOW YOUR OPTIONS, VISIT FIGHTCRC.ORG/SCREENING

OVER \$300 BILLION SECURED FOR RESEARCH



Advocates raised awareness locally, 46 states, 1 territory, and the District of Columbia all issued proclamations declaring March 2018 as Colorectal Cancer Awareness Month!



We saw 15 new co-sponsors (putting us over 200 total!) on the medicare loophole screening bill after our visits in March—and we continue to keep the pressure on!



Over 150 advocates from 33 states and 1 territory joined us for Call-on Congress this year—our largest group yet!

Immediate action in Congress is a rarity in Washington, but this year our Call-on Congress advocates got to see quick action and big results—positive change in the right direction!

For many months leading up to March 2018, Congress delayed funding the federal government. This uncertainty caused a multitude of problems for federal agencies and programs that provide essential services for colorectal cancer patients and the screening-eligible population.

At Call-on Congress, we armed 150 advocates with this information and our legislative asks. On March 20, Fight CRC advocates from 33 states engaged in over 170 Congressional meetings, 120 of which were with members of Congress or senior staff. They shared their concerns and most importantly, their stories. They raised their voices, covered Capitol Hill in blue and made sure the community was heard.

The impact was immediate and unquestionable.

A mere two days later, the House and Senate passed an omnibus appropriations bill for fiscal year 2018 (FY18) that increased funding for National Institutes of Health (NIH) in the amount of \$3 billion—\$1 billion over our ask—and included additional funding for National Cancer Institute (NCI). The bill also included a \$20 million increase for the Department of Defense (DoD) Peer-Reviewed Cancer Research Program (PRCRP) and it rejected the president's proposal to consolidate the Centers for Disease Control's (CDC) Colorectal Cancer Control Program. With a stroke of the president's pen on the afternoon of March 23, just hours before a government shutdown would take effect, the Consolidated Appropriations Act of 2018 became law.

WE CELEBRATED A HUGE VICTORY!

These increases meant federal agencies and programs can continue to serve the colorectal cancer community knowing the future funding of their programs is secure. It meant colorectal cancer researchers have more resources to keep up with, and potentially even hasten, the pace of research.

We know our stories remind representatives the policies they debate have an impact on real lives. Elected officials are in D.C. to represent us, and this victory shows many of them hear our stories and honor the courage with which we fight every day.

We have not let up on our advocacy, realizing every year there's an appropriations process that determines the government's investment in cancer research. But we've seen that when we advocate together, we make a big impact! We have no plans of letting up anytime soon.



JOIN US IN 2019!

OUR 13TH ANNUAL CALL-ON CONGRESS
IS MARCH 17-19, 2019! CHECK OUT ALL
OF THE DETAILS AT CALLONCONGRESS.ORG





Rep. Raskin speaking to advocates at the 12th annual Call-on Congress. He is a stage III CRC survivor representing Maryland's 8th district. Rep. Raskin serves on our Congressional Committee.

In 2010, Jamie Raskin received surprising news. After experiencing reflux symptoms, it was recommended he receive an endoscopy. Otherwise healthy, the 48-year-old law professor and Maryland state senator followed doctors orders—even when they suggested he get a colonoscopy, too.

Results from his endoscopy were normal, but his colonoscopy told a different story. A few days later it was confirmed he had stage III colorectal cancer.

"I woke up to nurses surrounding me and hugging me... a few days later once I was diagnosed it was off to the races."

Raskin "did it all," meaning radiation, surgeries and chemotherapy. Fortunately, he responded favorably to treatment and was declared "cancer-free." But although he now lives with "no evidence of disease," the experience never left him. He still gags when driving by the exit to the hospital where he received chemotherapy. And, he carries with him the weight of fighting for the millions of people still suffering and the researchers, scientists and others at the National Institutes of Health (NIH) whom he was elected to represent.

"I resolved to never forget my brothers and sisters going through this every single day. Millions are suffering from colorectal cancer or other cancers and diseases."

MISFORTUNE

Susan Sontag, an essayist who Raskin often quotes for her metaphor on illness, once wrote:

"Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place."

As Raskin made his entrance back into the "kingdom of the well," the then-state senator (who had continued to work during treatment) set his sights on an even big goal: Congress. He was elected to serve as the representative for Maryland's 8th congressional district in 2017.

Today, Rep. Raskin works on the Hill to champion healthcare and medical research. He emphasizes the difference between misfortune and injustice—and advocates for government policies that do not compound misfortune with injustice in people's lives.

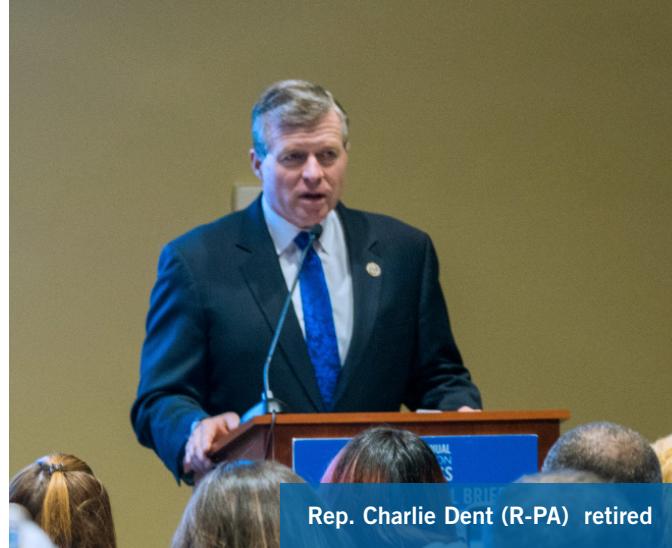
"If life is going well and you get stage III colon cancer one day, that's a misfortune. It happens to people every single day. But if you come up with a serious diagnosis, and you cannot get insurance or treatment, that's an injustice. We're the wealthiest country in the world. Nothing is more important to people than sick family members who need every possible advantage to get well. I advocate for a fully-funded NIH."

“

IT WAS A LEARNING EXPERIENCE;
I FELT FROM THE BEGINNING THAT
I'D GONE OFF TO A FOREIGN LAND
ALTHOUGH I NEVER LEFT HOME.

”

REP. JAMIE RASKIN
STAGE III SURVIVOR



Rep. Charlie Dent (R-PA) retired



Rep. Rodney Davis (R-IL)



Rep. Leonard Lance (R-NJ)

Our Congressional Committee provides guidance and staff support for better policies to address screening, awareness, regulatory and research issues related to prevention and treatment of colorectal cancer. The honorary members also foster a greater recognition, support and coordination amongst policy makers and advocacy efforts and lend their voices to advance outreach efforts.

MEET THE CONGRESSIONAL COMMITTEE!



Rep. Donald Payne, Jr. (D-NJ)



Rep. Betty McCollum (D-MN)



Rep. Phil Roe (R-TN)

MEET THE FIGHT CRC CONGRESSIONAL COMMITTEE



Steve Greene, stage IV survivor,
Fight CRC board member with
his wife, Shelton

LIVING LEGACY

5 NON-CASH GIVING IDEAS

Did you know nonprofits like Fight Colorectal Cancer run off of the generosity of donations and support from businesses and individuals?

While some may think making an online donation or mailing a check is the only way to donate, there's actually a lot of ways you can support an organization like ours.

Board member, stage IV survivor and wealth management advisor Steve Greene offers these ideas if you're arranging your financial plans and want to include this important cause in your portfolio. Here are ways to support a nonprofit with cash and non-cash gifts:

1. Your Will – Name Fight CRC in your will
2. Appreciated Securities (stocks, bonds, shares of mutual funds) – donate appreciated securities directly to Fight CRC
3. Retirement Accounts – Name Fight CRC as the beneficiary of your 401k or IRA
4. Donor-Advised Funds
5. Life Insurance – Name Fight CRC as the beneficiary of your life insurance policy

To learn more about these options and how they affect your financial plan, speak with a financial professional or tax advisor.



LEARN MORE AT FIGHTCRC.ORG

OH! THE PLACES ADVOCATES GO...

From walking across the country (yes, seriously) to bowling for a cause—check out some of the creative ways our advocates are honoring and remembering the One Million Strong (and raising money for Fight CRC at the same time)!



Cancer Stroll

Who: Advocate Chad Schrack

What: Walking across the country from Arlington National Cemetery to Venice Beach, California in summer 2018

Why: To honor his wife Sheila, a stage IIIC survivor and support fellow veterans

Follow his journey: FightCRC.org/CancerStroll

Excuse Me, Officer

Who: Town of Guttenberg, New Jersey

What: Mayor Wayne Zitt wrapped state police cars with One Million Strong colorectal cancer awareness messages!

Why: To support stage II survivor Bob Ceragno

Bowled Over

Who: Mike Hall and Severna Park Lanes, Maryland

What: Hosted a private concert with Fight CRC spokesman Craig Campbell at his bowling alley (and raised over \$10,000!)

Why: Honor Craig's work to raise awareness in memory of his father

Cheers!

Who: Ambassador Caity Grand

What: Helped coordinate a fundraiser at NYC's club Distilled, Cocktails for a Cause

Why: In memory of her mom

Rock On!

Who: Ambassador Alex Hernandez and Fall Out Boy

What: An avid fan, Alex was nominated to be Fall Out Boy's Champion of Dallas because of her advocacy with Fight CRC (the band donated \$2,500!)

Why: In memory of her mom



**READY TO PUT YOUR CREATIVE
FUNDRAISING IDEAS INTO ACTION?!**
CONTACT MICHELL BAKER AT 703.647.4694

SPARKS OF STRENGTH



Below are men and women we consider “sparks of strength.” Their legacies inspire all of us every day to fight with courage. Their loved ones have chosen to make a donation to Fight Colorectal Cancer to honor or remember them. It’s our honor to be trusted with keeping their voices heard.

Those listed below were honored/remembered through donations made from July 1, 2017 through Dec. 31, 2017. Dollars donated will support awareness, advocacy, research and education.

IN HONOR OF:

- Wanda Addy
- Patricia Alexander
- Mary Joan Arnold
- Evelyn Beato
- Michael Beaubien
- Jack Birren
- Jennifer Bracey
- Dianne Braley
- Mike Bridges
- Tyler Cass
- Bob Ceragno
- Merrill Culverhouse
- Margaret Finch
- Shelly Galletch
- Chris Ganser
- Harry Gooder
- Teri Griege
- John Grill
- Scott Gross
- Rita Haugner
- Eric Hausmann
- Alex Hernandez
- Afia Hussain
- Paul Hutchins
- Scott Johnson
- Greg Kearney
- Jasmina Kontic
- Andrea Kramer
- Rob Kramer
- Marra Lashbrook Rodriguez
- Melissa Link
- Melissa Lozoff
- Jill MacDonald
- John MacLeod
- Lewis Moore
- Chip Moore
- Darrell Moser
- Dollene Nicholls
- Eleanor North
- Kathy Oliver
- Penzer Family
- Michael J Robertson
- Dana Rye
- John Saraceno
- Joel Saxon
- Michael Scally
- Alex Schaefer
- The Schracks
- Pamela Seijo
- Sevier Family
- Judi Sohn
- Jim Stolting
- Joy Thomas
- Brian Threlkeld
- John Tiefry
- Jelena Tompkins
- Sean Twersky
- Kamen Williams



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



SPARKS OF STRENGTH: Looking for a meaningful way to remember a loved one or celebrate with a survivor? Host a Sparks of Strength. This event can be as big or little as you want. Customize it to fit your needs. Get more info at: FIGHTCRC.ORG/SPARKSOFSTRENGTH

IN MEMORY OF:

- Laura Acquisto
- Margaret Finch
- Deano Langston
- Mary Purdy
- Latonya Adkins
- Roy D. Galvez, Jr.
- Stephen Lindenbaum
- Rosetta Ragusa
- Dr. Edward L. Anderson
- Serge Ganthier
- Terry Lynn Pace
- Maureen Regan
- Matthew Aydelott
- Paul Gartman
- Bill Malthouse
- Richard Crafts
- Steven Baker
- Emma Gaytan
- Nancy Malthouse
- Angie Richardson
- Kurt Barbour
- Daniel Geiger
- Tom Marsilje
- Frank Riesenbergs
- Daniel Beber
- Nelson Gibson
- Patti Martins
- Christopher Rosebrugh
- Vickie Bingham
- Andy Giusti
- Stephen Mayberry
- Mary Ann Sagdahl
- Loraine Blondell
- Jim Goessling
- Margaret McCarthy Kelley
- Anne Marie Schaar
- Kathy Boyle
- Mark Gottman
- Cheryl McPhearson
- Robyn Schmid Tiffie
- Bradley Brahms
- Joni Haas
- Ashley McRoy Disney
- Cynthia Schmidt
- Fred Brazel
- Rose Hausmann
- Rob Michelson
- Chief Alvin Scully
- Heidi Cardiff
- Neal Hechtkopf
- Elizabeth Miller
- Captain Nolan Shipman
- Robert Chalmers
- Herbert Allen Hibler
- Simeon Miller Jr
- Elkie Silver
- Jonathan Claudy
- Todd Hope
- Thomas Mitchell
- Dick Singer
- John Concannon
- Victoria Hope Davis
- Ilo Mojsovski
- Charlie B. Smith
- Sandy Connolly
- Regina Huffman Eubanks
- Clarence Mulder
- James Smith
- Devery Crow Jenkins
- Kindra Jackson
- Kate Murphy
- Jay Varacalli
- Clint Cummings
- Jill Christman
- Mary Lee Myers
- Jerome Villavecchia
- Rosanna DiLemme
- Scott Johnson
- John Naughton
- Michelle Lynn Von Feldt
- Josien Doornink
- Ton Jurriens
- Lena Oneacre
- Jennifer Wesselmann
- Lisa Dubow
- Louis Kastelberg
- Karen Parkison
- Doug Wilson
- Tim Elsbernd
- Lauren Kehl
- Aunt Patti
- John Winters
- Michael Evans
- Robert Kitchen
- Rashmi Patwardhan, MD
- Timothy Zalusky
- Alice Fay Farmer Barnette
- Dieter Klose
- Jon Pawlowski
- Ken Zuroski
- Shawn Felty
- Merlene Knuchell
- Lynne Pettler
- Victor Fernandez
- Charles Kramer
- Belle Piazza

MAKE SURE YOUR LOVED
ONE'S NAME IS LISTED IN
THE NEXT *BEYOND BLUE!*



VISIT GIVE.FIGHTCRC.ORG
OR CALL 703.548.1225
TO MAKE A DONATION.



**FIGHT
COLORECTAL
CANCER**

get behind a cure.®

Denise Jonas, caregiver
Twitter: @MamaJonas

TAG US **@FIGHTCRC**
POST YOUR **#STRONGARMSELFIE**

BEYOND BLUE

Beyond Blue is a magazine for those facing colorectal cancer produced by Fight Colorectal Cancer each fall and spring. Each issue is hand-carried to medical offices in the United States (and Puerto Rico!) by a group of distributors made up of survivors and caregivers, medical professionals and advocates committed to the cause. They're all passionate about our vision: victory over colon and rectal cancers.

Genentech

 MERCK ONCOLOGY



To become a sponsor, call 703.647.4694 or email Fundraising@FightCRC.org

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