

Zac Getty:

Good afternoon everyone, or good morning if your time zone is different than me. My name is Zac Getty. I'm the patient education program manager at FIGHT CRC. Thank you all for joining us today for our colorectal cancer screening options webinar. FIGHT Colorectal Cancer is the leading patient empowerment and advocacy organization in the United States, providing balanced and objective information on colon and rectal cancer research, treatment, and policy. We are relentless champions of hope focused on funding promising high-impact research endeavors while equipping advocates to influence legislation and policy for the collective good. Before we get started with the actual webinar, let me go through a few housekeeping items for everyone.

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We will have some time at the end of the webinar for general questions, but please feel free to ask any questions that come up along the way in the Q&A panel on the right side of your screen. We generally won't interrupt the webinar to answer any questions in the middle of it, but please get them in there. We will address them at the end of the webinar, and we will do our absolute best to address any questions that are asked. We will have a recording of this webinar available on our site within the next few days, and you will also receive a direct link to that recording via email as soon as it is available, if you've registered for this webinar. We will also provide a written transcript of the webinar on our site for those of you that would prefer to read the information discussed today as opposed to watching it, and also feel free to tweet along with us. You can use the hashtag CRCWebinar.

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Please remember to stop by our website at fightcrc.org to check out all of our patient and caregiver resources. This includes your guide and the FIGHT meetups, which are an online space to meet with other patients and caregivers that are held three times a month. They touch on a variety of topics but are also just a great place to find a sense of community and chat with other people that have had similar experiences as you. We also have our free Community of Champions app where you can connect with other people in the colorectal cancer space and keep in touch with FIGHT CRC and know what we're up to, and we also offer an assortment of print and digital educational resources that are free to request and download from our site.

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Quick disclaimer, the information and services provided by FIGHT Colorectal Cancer are for general informational purposes only. The information and services are not intended to be substitute for professional medical advice, diagnoses or treatment. If you are ill or suspect that you're ill, please see a doctor immediately. In an emergency, call 911 or go to the nearest emergency room fight. FIGHT Colorectal Cancer never recommends or endorses any specific physicians, products, or treatments for any conditions. Okay, so with all of that out of the way, I would like to briefly introduce all of our participants. Joining us today are Dr. Fola May, FIGHT CRC medical advisory board member and ABGH co-founder, as well as Mark Moore, Shawna Brown, and David Sheir, all three of them survivors. David is a current FIGHT CRC ambassador and Mark is a former ambassador, and they'll all be sharing their screening experiences with us a little bit later on in the webinar. Dr. May, Mark, Shawna, and David, thank you so much for taking the time out of your busy schedule to join us today. Dr. May, I'm going to hand it off to you so you can provide a little bit more information about your background and kick us into the actual webinar.

Fola May, MD:

Thanks so much, Zac, and it's good to see everybody. Hi, David, Mark, and Shawna. I'm actually most excited to hear your stories in a little bit, but I will get us started. My name is Fola May, as Zach mentioned. I am Zooming in from Los Angeles where I work at UCLA. I also work in the Veterans Affairs where I take care of patients. I'm a general gastroenterologist. I do a lot of colonoscopies, a lot of polyp removals, and I also run a lab that focuses on preventing colorectal cancer, detecting it early, and getting screening tests into the hands of all types of people regardless of their background. Next slide.

Fola May, MD:

I'm going to start with some introductory information today just about the importance of screening and the different screening tests, and then after that we'll hear from our other panelists and hopefully we'll have some great questions from our audience as well. The first question is, why is screening important? I'm going to start with some general statistics about early onset colorectal cancer or EAO, and really we want to pay attention to this because this is a recent phenomena that we've seen in the epidemiology of colorectal cancer. I always like to remind people that it wasn't too long ago that we really considered this disease something that only happened in older people, people in their sixties, seventies, and eighties, and that's no longer the case. Unfortunately, we are seeing colorectal cancer in younger and younger people. Of all cancers, colorectal cancer will take the most lives of people under age 50 by the year 2030, and that's a remarkable statistic, and that was released about a year ago, that we learned that looking at modeling data.

Fola May, MD:

We think that the number of cases of early onset colorectal cancer under age 50 is going to increase by about 140% by the year 2030, which equates to about 27,000 additional people under the age of 50 being diagnosed with this disease in the next few years. When we look at adults under 50, colorectal cancer is actually number one in cancer related deaths for men and number two for women. The reason why that's big news, and the American Cancer Society released that report just about a month ago, is that previously it was number four for both men and women under age 50, so that's a big jump, going from fourth place to first for men and fourth place to second for women. We also know that the number of patients in the United States diagnosed under age 55 doubled, from about 11% to 20%, from the years 1995 to 2019. That's some numbers on paper just to demonstrate what we're dealing with. We're dealing with a disease that is kind of changing in its character, and it still continues to affect older individuals who are over 50. That group, it still remains to be the biggest group affected, but now we also need to focus on our younger populations as well. Next slide.

Fola May, MD:

Coming out of that younger group and looking at colorectal cancer in general, in 2024, the American Cancer Society estimates that there'll be about 153,000 cases of colorectal cancer and about 53,000 deaths from this disease. In 2020, there was an estimated 1.4 million people living with colorectal cancer in the United States, so a lot of our efforts do focus on finding this disease early and preventing it, but also on our survivors and what we can do to enhance their quality of life, as well. Currently in the United States, when you look at people across all ages, it's the third most common cause of cancer related death for men and women. When you combine men and women and you look at deaths, it actually rises to the second most common cause of cancer related deaths, so even when we're looking at populations that aren't under 50, significant burden of disease. Next slide.

Fola May, MD:

Family history of colorectal cancer is found in about 20 to 30% of people who are diagnosed with colorectal cancer, so it is something we pay attention to. There is this fallacy in the public that you can't get colorectal cancer unless you're in your family, so we're really trying to fight that and educate everyone that we are all at risk. Yes, there is an increased risk for people who've had a mother, father, brother, or sister with colorectal cancer, and we screen those individuals earlier, which I'll talk about in a minute. Between 25, or, I'm sorry. All people with a first degree family member, so again, that's going to be a mother, father, brother, or sister, should start screening at age 40. That's the latest they should start, and if you've had a family member who in particular had colorectal cancer at a young age, you're actually going to start your screening 10 years before that family member was diagnosed with colorectal cancer. The example is, if you had a brother with colorectal cancer at age 35, we're actually going to start screening you at age 25, 10 years before your brother was diagnosed. Next slide.

Fola May, MD:

Right now, we have a very effective way to prevent what we think upwards of 60, 70% of colorectal cancers and deaths, but unfortunately, not all people participate in screening. We know that one in three individuals aged 45 to 75 in the United States is not getting screened, and this is despite national guidelines that say that everybody in this age group should be screened. This equates to about 20 million Americans who are eligible for colorectal cancer screening, who are walking around all day, who haven't been screened, who might be growing polyps, who might be growing cancers, and a lot of our efforts in March, which is Colorectal Cancer Awareness Month, are to get those people aware of their risk and into doctors' offices so that they can get screened. We know that in 2021, about 20% or fewer than 4 million of the 19 million eligible adults were up-to-date for colorectal cancer screening, so again, this is millions of people that we're talking about, and the number of patients in the United States diagnosed with advanced stage colorectal cancer increased from 52% in the mid-2000s to 60% in 2019.

Fola May, MD:

This is important because the stage that we diagnose your disease matter. I like to remind people that if we can diagnose your colorectal cancer at stage one, your survival, your likelihood to survive, is over 90%, but if we cannot diagnose it until stage four, your survival drops all the way down to 13%, and that's why advanced stage cases are important, and we want to reduce the number of advanced stage cases, and if we're going to find cancers, we certainly want to find them early where they're curable. Next slide.

Fola May, MD:

Who needs to be screened and when? We've gone over this a little bit, but I want to emphasize again that the first thing you need to know to answer this question is whether or not there's a family history. When people approach me and say, "Do I need to be screened?" The first thing I say, "Do you have a family history of colorectal cancer, and specifically in a mother, father, brother, or sister?" If they say yes, then I consider them elevated risk, and that individual needs to start screening at age 40 or 10 years before the earliest family member was diagnosed. If there's no family history of colorectal cancer, then we consider you average risk for colorectal cancer. All of those individuals need to start screening at age 45, so the latest that anyone should start screening for colorectal cancer is age 45, and earlier if there's a family history. Next slide.

Fola May, MD:

I'm going to spend a few minutes now to talk about the different screening options for colorectal cancer. We're actually pretty lucky, because with colorectal cancer, there are a few ways that you can get the job done and get screening done. For other cancers that we screen for, there's really only one, maybe two tests. For colorectal cancer, the United States Preventive Service Task Force actually recommends seven different strategies to get up-to-date for screening. The most common is the colonoscopy. We do consider this the gold standard, meaning that this is the test that's going to find the most cancers and polyps, although it's not perfect, it does miss things sometimes. The challenge with this type of testing is that it does require a bowel prep. You need to drink a laxative the day before the procedure to clear your colon of all stool and material, so that means that you're on the toilet for quite a bit the day before the procedure. Some people don't like that day. A lot of people tell me that that's the worst day, the worst part of the entire process, is getting the laxative and getting the cleaning.

Fola May, MD:

When you get through that, it's the next day that you come in for the procedure, which is usually performed at a hospital or outpatient surgery center. It's usually done by a gastroenterologist, but we do have some surgeons that do colonoscopies as well. The colonoscope is a long flexible tube and has a camera at the end. We pass that through the rectum into the clean colon, because remember, you've taken the laxative the day before, and we're allowed to visualize the walls of the colon. We can take out any polyps we see. That's important because colorectal cancers always come from polyps, so if we can take out the polyps, then those polyps don't have a chance to develop into cancer. The tricky thing is that not all polyps become cancer, so when I'm doing a colonoscopy and I see a polyp in the colon, I don't know if that polyp is going to become cancer. We just take all of the polyps out, and that's the benefit of colonoscopy, is that you can get that all done in one go, is you can get the screening test and the polyp removal. If you have no polyps, then you repeat the colonoscopy in 10 years. If you have some polyps, you might need to come back as frequently as every three years, but it's usually every five to 10 years. Next slide.

Fola May, MD:

Colonoscopy is not for everyone. It does require you to take a day off, usually during the days of the week when gastroenterologists or offices are open. It does require you to do the prep the day before. Some people can't do that, so we're actually very lucky that we have other options for screening. Now, if you have a family history of colorectal cancer, you should not do this option, but if you don't have a family history of colorectal cancer, this option is one that you can do. It's called the fecal immunochemical test. That's a lot of words, so we call it the FIT test. This is an at-home stool test. You have a normal bowel movement into the toilet bowl. It comes with instructions on how to cleanly collect a sample of that stool, put it into a container, and send that off to a laboratory. What they're looking for in the stool in the laboratory is small amounts of blood.

Fola May, MD:

People like this test because you're going to do it at home. You don't need to take a day off of work. There's no prep involved. You don't have to have a procedure, but the reality is it's a two-step process. About 10% of people will have the test show, light up as abnormal. Those people need to go and have a colonoscopy. If you don't have a colonoscopy after the abnormal or positive result, then there might be a polyp or cancer that you're ignoring in your colon. Next slide.

Fola May, MD:

The other test that's become very popular is called the FIT-DNA or MT-SDNA. This is what you see the commercials call the Cologuard test. It's made by Exact Sciences. It's a similar process. You have a bowel movement at home. This time, it's a bigger container that you put actually a larger sample of stool in, and you send it off to a laboratory, and they are checking not only for blood this time, but they're checking for DNA that can be consistent with DNA from cancer or polyps. This is a little bit better at finding polyps, a little bit better at finding cancers. The other benefit from this test is that you only have to do it every three years. The test we talked about just before this, the FIT test, you have to do every year. Both tests, however, like I said before, require a colonoscopy if it lights up as positive or abnormal. Next slide.

Fola May, MD:

Great, so now I get to pass it back to Zac. Thank you.

Zac Getty:

Thank you, Dr. May. I appreciate it. Now we've got an opportunity to talk to Mark, Shawna, and David about their personal experiences with the three tests that Dr. May has gone over. I'm going to start with Mark, here. Hi, Mark. How are you?

Mark Moore:

Hi, how are you doing?

Zac Getty:

I'm doing well. Thank you for joining us today. You were screened using a colonoscopy, correct?

Mark Moore:

Yes, yes, back in 2020. First of all, I want to speak to everyone that's attending this seminar today. I'm glad that you guys are here, and I'm hoping that you'll hear something to take into consideration if you are dealing with something that you may be afraid of, or hoping that it would enlighten you to take this seriously. Back in 2020, we all know 2020 came in with a bang. We had COVID, we had Kobe, and I had an accident or something, but back before then, it was late 2018, 2019. I was visiting my doctor here in Durham, North Carolina, and we seen some traces of blood, and one day, something in my blood work, and he asked me, said, "Mr. Moore, anybody in your family ever had colon cancer or colorectal cancer?" I said, "No, not that I know of." He said, "Looks like we had signs," and it was just, having a great relationship with your doctor is really important, but we was having a normal conversation. When he said, I said, "Doctor, you said that like ... " He said, "Oh, it's okay if we did. We caught it early."

Mark Moore:

2020 came in. He gave me this prescription to get my colonoscopy, so we set it up, but colon cancer was running so crazy, so I ended up taking it in May. Never forget it, the Monday after Mother's Day, we went in, and of course you had to take the solution. I did the solution, and I knew that it was important, and in the back of my mind, thinking of what Dr. Evans and I had just discussed. I was like, "Okay." It was no problem. I did take the solution and we went in that Monday morning, and it wasn't bad at all. It was some of the best sleep, was some of the best sleep, but one of the things that I noticed that ... Then, this was my first time. I'm 50 years old. I was 50 at the time, and it was two polyps. I looked at my screen, they give us a screen, a photo of it afterwards, and I noticed it was two polyps, one real small and one big. I didn't think anything of it. This was my first time.

Mark Moore:

Never forget that Friday morning, I was on the phone, I was seeing the doctor call me back. He said, "Hey, Mr. Moore, we told you we'll send the polyps off to get tested, and one of them came back and it tested positive for cancer." I was like, "Whoa," and the strangest thing with so much going on in 2020 was, I never was afraid until after it was over with. I kept it a secret a long time from a lot of my family members and friends. I tell anyone now, "No, don't do that." Build a support team, have a support team around you, and it's really important. The most important thing of having that colonoscopy is building a great relationship with your doctor. Not just then, but before, now, if you're seeing your primary physician or anything, have that, build a relationship. Be able to talk to that doctor with openness and share with him or her things that you're going through. It's so important. It's so important, and I tell anybody, this was the best thing that happened to me, with having that relationship, because we caught mine early. I was a stage one, and when I said about having a support team, FIGHT CRC have been in my corner along the way.

Mark Moore:

We had a chance to go out and meet a lot of survivors, and some patients now that's dealing with cancer right now from all around the world, and we had a chance, I'll never forget this day, and it's so important. We had a chance to share our story through a painting seminar, and one of the things, as I was listening to everyone share this story, I was like, "Dang, my story is not that important because people are really going through it." One thing that I never would tell anybody, it's something that it was good, but what happened, it took me ... Being a survivor has taken me places where I never would dream of, and it was so important that I share my story to make sure that you get screened early. Don't let anyone dictate your health to you. If you have any type of feelings, odd feelings, you talk to your doctor, ask them. Sometimes they say, "Oh, you're too young." No, I done seen too many horror stories about being too young. Please, take it serious and make sure you're taking care of yourself and eating healthy, but most of all, build that relationship with your doctor because this is one of the best things that I had.

Mark Moore:

By catching it early, so many people are not fortunate enough to have that, and I don't want to see anybody else go through this. Also, like I said before, make sure that you have a support team around you. It's a lot of support groups out there, but I tell you, FIGHT CRC has really been great with me and I want to thank everybody that's up here now and the panel, because this is really important. We're looking at the numbers today of what we're predicting in the future. We don't want to see that. We don't want to see that anymore.

Zac Getty:

Thank you, Mark.

Mark Moore:

Thank you, guys.

Zac Getty:

Yeah, I appreciate it. You got a lot of advice in there, which is really great advice. Do you have any practical advice for people that might be getting ready for a colonoscopy, with the prep or the actual

procedure? Anything that stands out to you that you might suggest to anyone getting ready to go through that?

Mark Moore:

One of the things that I've done, I did the over the counter, and it was the Gatorade and the prep. One of the things I do, I tell anybody, just drink it. Just drink it. Just don't think about it. Just drink it. Get it over with. Just drink it, and it's tough. It's tough, but once you put your mind ... You're just sort of thinking of other things that you just say, "Look, I'm going to just drink it." You have to have a mindset and say, "This is important for me to do. This is a matter of life and death." Sometime it really is, and so that's one of the things when you're prepping for it, is making sure that you have an open mind and you're thinking positive. You think positive. Make sure, "Hey, I'm going to be okay. I'm doing this because I want to make sure, assure myself that I'm good."

Mark Moore:

That's something that I would tell anyone, is just that you're taking it because of precautionary measures, that you want to make sure that, "Oh, I don't have to worry about anything coming up. I'm not going to put it off. I want to do it right now." If you have put it off a little bit, please, please, by all means, take that next step and go and do it. Prepare yourself mentally, and it's not that bad. I will, like I said before, when they put you out, it's some good sleep. It's some good sleep.

Zac Getty:

Thank you, Mark. It sounds like the actual test isn't that bad once you've gone through the prep and you show up for the test, so get a good nap out of it and enjoy it for what it is, I suppose.

Mark Moore:

Yes.

Zac Getty:

Thank you so much, Mark. I appreciate you sharing your story. Shawna, I'm going to move on to you, if you don't mind. You used the fecal immunochemical test, is that correct?

Shawna Brown:

Yes, yes.

Zac Getty:

Excellent. How old were you when you got screened, when you used that test?

Shawna Brown:

Good morning, everyone. I was 49. 49, on a routine visit. Didn't know that they had just lowered the screening rate from 50 to 45, at that time, so my provider, because yes, I do have a good relationship with my provider, she said, "Hey, we need you to take this test, because we're finding cases earlier than 50." Mind you, I had been getting the test in the mail, but I ignored it because I thought, "Well, I'm not 50 yet, so I'm waiting. I'll wait until I'm 50. I'm not 50 yet." She convinced me to take it, and what she advised me to do is just put the test in the bathroom so that when it comes to mind, you can go ahead and prepare to do the test, take the test.

Zac Getty:

Excellent, so you were kind of caught in that in-between stage where the screening age had been lowered and you already passed it, but hadn't hit 50 yet. Correct?

Shawna Brown:

Correct.

Zac Getty:

Interesting. Did you have any symptoms or anything or was it just, they just gave you the test because it was time to get screened?

Shawna Brown:

Yeah, I didn't have any signs or symptoms. They just gave me the test and said, "It's time for you to take it."

Zac Getty:

Excellent, thank you. I think that's an important point to make, if I can, that there are signs and symptoms of colorectal cancer, but sometimes there are no signs at all. What was taking the test like for you? Was it easy to use? Was it difficult? I know people kind of get squeamish when it involves things, taking tests at home. What was your experience like?

Shawna Brown:

The funniest thing, that when I thought about this test before doing it or having it in my possession, I thought it was probably one of the nastiest things that you could do, right? To put something in a container and put stool in the container, and have to mail it. I just couldn't ... I feared that, and so she explained to me how to do it. My provider opened the kit and showed me visually, and so I kind of had an idea of what it would look like, and so when I got home, I did it. It was simple, it was easy. It really wasn't that bad. It's not this big mess that you may think of. It's really very simple, and it was easy, and once I did it, it made me feel better. I mean, because of all the fear that I had before it. I think it's really having the time and the relationship with your provider to kind of help you go through the process, and I mean, I think it's great that she pulled it out, showed me what to expect, so I kind of knew. I went ahead and I was able to do it, and it was easy.

Zac Getty:

Excellent. Can you kind of share your story a little bit, maybe after you took the FIT test and sent it in? What were the next steps for you?

Shawna Brown:

I sent it in and I ended up getting the call back from the physician to say that the test was positive and they wanted me to come in for the colonoscopy, so I had to come in for that.

Zac Getty:

Then, that showed positive. What stage were you diagnosed at?

Shawna Brown:

Stage one. The provider that did or performed the colonoscopy stated that he really saw something that looked abnormal to the eye and he had a tough time removing it, and so yes, he removed the polyps. I had a few of them. He removed them, and I got the call back to say that it was cancerous. I think that was September of ... September, '21, and I went into surgery in October and they removed a piece of the colon away, and I was cancer-free after surgery.

Zac Getty:

Thank you, and so just to kind of wrap that up, any advice for anybody considering using a FIT test, or any practical advice that you might have for anyone?

Shawna Brown:

My advice to everybody is do it, because if you have the symptoms and the signs, you'll probably run into problems. It's the preventative piece. It's, when the providers say that this is the time to take the test, please take the test. I really didn't have a lot of information about it, and so I'm on the ground now trying to educate the community. I'm looking at all of the resources that FIGHT CRC has so that I'm able to facilitate that conversation and provide education. I'm working with the providers here in the facility, I mean, in the community, about really showing up in the community to say, "Hey, you guys, it's important. Please take the test. Don't be afraid." Have that relationship, like Mark said earlier, with your providers. Get to know them, get to share how you feel, but my advice to everybody is, please take the test. Just take the test.

Zac Getty:

Thank you. Thank you, thank you, thank you for sharing your story.

Shawna Brown:

You're welcome.

Zac Getty:

David. I've got you up next. How are you today?

David Sheir:

Good. Good afternoon, everyone. Thanks for having me here.

Zac Getty:

Good afternoon. Thanks for coming. We appreciate you joining us. David, you use the FIT-DNA/MT-SDNA screening test. People would know it more likely as Cologuard. It's on commercials, everything like that. What age were you when you used that test?

David Sheir:

I was 51 years old.

Zac Getty:

Okay. Was there a specific reason you used that or why you chose to get screened with that? Were you having symptoms, or did you just end up taking that test?

David Sheir:

Yeah, so I'll tell my story and then at the end I wanted just to give a couple of pieces of my experience and advice.

Zac Getty:

Great.

David Sheir:

I lucked out, because I was going to a doctor, physician, primary care physician every six months as part of my regular cholesterol screening and blood pressure medication, and my primary care physician was moving out of my market area and she asked if I would see her partner, and I said, "Sure, that's not a problem," so the next six months came and I met her partner. He, because I was a new patient to him, did a very deep screening, physical, and at 51, he simply asked me, "Have you ever had a colonoscopy?" I said, "No," and he said, "Well, do you want one?" I said, "No," so he said, "Will you at least take this Cologuard test?" He explained it to me, and basically the box gets delivered to it, and you do your business in the box and you ship it away, so I said, "Sure, go ahead and order it for me." This was in February of 2019.

David Sheir:

I go back to see him in August of '19 and he says, "Well, where's the results? I never got them." I said, "Well, I never took the test. It's been sitting in my home office." He said to me, "I'll tell you what, if you don't come back to me with those results, you can't see me as a patient anymore, so you have to take the test." I said, "Okay, this guy's serious. I'm going to take the test." I went home, I took the test. It was easiest thing in the world. I'm a guy who doesn't like gross things, but it was far from being gross. It was fine. It was easy. It went off. Results came back in a couple of weeks. He got them, they called me up. It came back positive. Being the kind of guy that I am, I started Googling, Dr. Google, right? Dr. Google told me that there was a ... I don't remember the numbers. I'm sure Dr. May knows better than me. Maybe there was an 8% false positive, right, so I'm thinking, "Okay, great, I'm one of the false positive people," so I didn't do anything about it.

David Sheir:

A month later, and by the way, I have no family history of colon cancer. I had no symptoms at this point, of colon cancer, zero. However, after the test came back positive and I sat around thinking I'm part of the 8% with the false positives, I did, for the first time, I'll never forget. I was at a business function, in the restroom. I did have some bleeding from the rectum, and that's when I knew things were serious, so I immediately got ahold of a gastroenterologist. I did the colonoscopy. I was fearful of the colonoscopy. It was much easier than I thought. It's about a 24 to 36 hour period where you start the prep, late in the afternoon. I recommend doing it on a Thursday afternoon, have the colonoscopy Friday morning, recover over the weekend, although you're going to recover very quickly. It's not bad at all, okay?

David Sheir:

Colonoscopy came back, so now it's a Friday morning, 7:30 in the morning, had the procedure. By 8:00, literally it's a half an hour procedure. Okay? By 8:00, my wife and I are sitting in the waiting room. The doctor comes out, the GI comes out, and just by the look on his face, I had known it was not good. He said I had 18 polyps, two of which were cancerous, and he was going to send it off for a pathological report, and he would let me know. Brought me in a couple of days later, and sure enough, they were

cancer. It was actually two. Well, I found out later. It was two separate DNA-identifiable cancers, so I'd actually gotten colon cancer twice, because they were two separate tumors in terms of DNA structure. In any event, I called some friends in the medical community. They connected me with a colorectal surgeon. I had surgery in November of 2019. They resected or took out about 12 to 14 inches of my colon. It was a surgery that lasted five hours in my case, particularly. Went through my belly button laparoscopically, took out all of the cancer plus some of the lymph nodes.

David Sheir:

The reason why is, I was diagnosed as stage three B. Stage three has three sub-stages, A, B, and C. You're basically one stage away from being stage four. Three C, and then stage four. I had the surgery. I was there again, maybe a Thursday, Friday, Saturday, got released on Sunday. I was lucky enough to get some great care team, an oncologist who right away ordered a Signatera test, which is another conversation, where it detects whether or not you have circulating DNA in your blood. They staged me again, stage three C. the colorectal surgeon conferenced with my oncologist, and they decided that I was going to go on chemo. I went on chemo in January of 2020, a regimen called CAPOX. Again, that's a whole different discussion, and I did chemo for six months, and then after the chemo ... Again, once you get diagnosed, there's a five-year window where you're getting screened all the time. I would go in every three months for CT scans and blood work, and then every six months. I'm happy to say we'll be hitting my five years this June and I am cancer-free. Yay. All along, and so that'll end my five-year window, and I couldn't have asked for a better outcome. I'm a very fortunate individual. I was blessed. I probably would've waited longer, if I ever had done it, and could have easily have been like many of my friends, unfortunately, in stage four.

David Sheir:

I'm very thankful and I'll be happy to answer any questions. Some of the things, and let me talk about the test itself. I can't say enough good things about the Cologuard test. It is, if you're like me and you're anxious or nervous or you think you're being inconvenienced or you're too busy in your work, at least at a minimum, like Dr. May said, if you don't have any family history, take the Cologuard test. It's the easiest thing in the world. Colon cancer, and again, I'm not a doctor, but I'll tell you based on my experience and my research, because I tend to geek out on things that I'm involved in. Colon cancer, if not is the only, but it certainly is the most preventable cancer in the world. You have to have a polyp before you can have colon cancer, so if you can find out if you have polyps, you can prevent colon cancer, provided it hasn't been too long, and that's the key. FIGHT CRC is the organization that got the age down from 50 to 45, but we are seeing a ton more people under 45 getting stricken with colon cancer. I would say at a minimum, do the Cologuard test. It was the easiest thing in the world.

Zac Getty:

It sounds like your advice for anyone considering using this test is just to do it.

David Sheir:

Yeah, just do it. It is a very low barrier to prevent, detect before it's too late, one of the leading causes of death in cancer.

Fola May, MD:

I like it. It's like the Nike ad. Just do it.

David Sheir:

Yeah, just do it.

Zac Getty:

Absolutely, and I do want to point out, I feel like that was a similar thread that ran through Mark, Shawna, and David's experience, was, just get screened. Just get screened. If you're past the screening age, just get screened. If your physician wants you to do it, just get screened. If you're average risk, just get screened. If you're high risk, just get screened. We can't tell you if you have cancer if you're not being screened, so I think that's really a huge takeaway from these three stories, if I had to summarize them. Thank you to the three of you for sharing your stories. Thank you, Dr. May, for going over some of the statistics and screening methods. I am going to open it up now for some, a little Q&A session. If anybody has any questions for Dr. May, David, Mark, or Shawna, please feel free to use the Q&A panel in the Zoom app there.

Zac Getty:

I do have a couple questions that have come through while Dr. May was speaking earlier, so I'm going to go ahead and relay those to her, but we do have some time here to answer any questions anyone might have. The first one I have, Dr. May, these are some pretty specific questions, so this one's relating to colonoscopy, I assume, because it's talking about prep, but how is the prep different, or is it different, for those that are taking Ozempic? I know that drug is kind of in the news right now. A lot of people are using it. Is there any difference in prep for those people?

Fola May, MD:

Okay. Yeah, it's a good question. Ozempic is one of the newer weight loss and diabetes medications that has come on the market. You've probably heard them, they're widely popularized in the media. They can lead to very significant weight loss rapidly, and are indicated for people who have diabetes and overweight. There's a few of them like this, and we've been very mixed in our messaging about what to do if you're on Ozempic and you need a colonoscopy. Anesthesiologists for a long time were telling patients to stop the medication for one or two weeks. In November, I think it was around November, the American Gastroenterology Association, the AGA, came out with a statement saying that we do not think that you need to alter your Ozempic dosing when you are getting a colonoscopy. The data are still very light, because we don't have that many cases to look at, but there's no indication to us that you need to interrupt your usage of the medication.

Fola May, MD:

The caveat I'm going to say, though, is that you need to follow the rules that are set by the surgical center or hospital where you're getting your procedure. If they're telling you that they want you to stop, you've got to stop, because they're not going to do the procedure if you show up and you said, "Well, Dr. Fola May said I don't have to stop," so do whatever they say, but we are encouraging health centers around the country to have patients just continue these medications as usual.

Zac Getty:

Thank you. Here's one that I've actually encountered recently. Can you speak to some of the FIT tests that you can get from drug companies or over-the-counter drug stores? Are those the same as the FIT test that you might get from your physician via prescription and send in? Are they different? Are they equal, equitable, all that?

Fola May, MD:

This is back to the FIT, which is one of those stool-based tests. The beauty again of these is that they're very convenient. You can do them at home. One of the unfortunate things that's happened, though, is that it's become kind of a marketing game in the sense that now there are hundreds of these on the market, nationally and internationally. I think someone counted and there were 225 different types of FOBT and FIT tests. It's tricky, right, because I'm going to be the first person to tell you they're not all equal. Some of them are much better than others. There was a group that did some studies actually about four years ago, and highlighted that about six of them are probably better to use and safest to use, and so we do tend to recommend those, and those are the ones that are used in hospitals and health centers.

Fola May, MD:

That's why I do kind of prefer when people get their FIT tests from a doctor, because the clinics are going to use one of these verified tests, but they are becoming available at CVS. You can order them online. I've seen them at health fairs. You want to make sure that if it is labeled FOBT, that it is a high sensitivity FOBT, and you want to make sure that if it's labeled FIT or F-I-T, that it has been tested and that it's verified as an effective test. I think if you have a choice, I would prefer you get it from your doctor or your clinic, your primary care provider or gastroenterologist, just because those ones have been tested and we know how well they perform.

Zac Getty:

Thank you. Kind of a two-part question here about the actual kind of behind the scenes with a colonoscopy. One, is it possible to see the appendix during a colonoscopy? Two, is it common for patients to have a colonoscopy, the physician doesn't see polyps, but it turns out there actually were polyps there?

Fola May, MD:

Yeah, I love the first question. Yeah, I get to see the appendix when I do colonoscopy. I'm such a weirdo in that I love the colon. Just even before I went to medical school, I thought the colon was the coolest organ. Yeah, when we're in that, inside there, actually our goal is to get to the appendix. Now, we don't go down the appendix because the appendix is very narrow and we can rupture it if we go down it, but when I'm teaching my fellows how to do a colonoscopy, they're not done until I see that appendix. We call it the appendicial orifice. That's the entry point to the appendix and it marks the end of the colon. Everyone's always happy when they get to that point because we know we've examined the entire colon, so that's a good question because it kind of is where we celebrate during the procedure. The second question I think was about missing polyps. Yeah.

Zac Getty:

Yeah, it was, what percentage of patients where the doctor doesn't see polyps and there actually were polyps there? That may be tough because it's hard to prove a negative, but ...

Fola May, MD:

Yeah, well, I don't have that number, but what I can tell you is that 1% of colorectal cancers were missed during colonoscopy. It doesn't sound like a high percent, but given that we perform a million colonoscopies a year in this country, that's quite a significant number of missed cancers. I'm not talking about missed polyps, I'm talking about missed cancers, so even though we call colonoscopy the gold

standard and that that's the best test, it's not perfect. I alluded to that when I was talking earlier. You want to make sure you go to someone who does these regularly, who has a high case number. Some of our health centers, we're starting to even report our quality data, so some health centers will even be able to tell you how good or bad a doctor is at finding polyps. I really do recommend against ... I recommend against going to someone who is a different type of doctor that just does these on the side. You really want to go to a gastroenterologist or surgeon that does these regularly.

Zac Getty:

Thank you. A couple more here, which, thank you for everyone, for asking questions. Please feel free, we've got about 15 minutes. We get a question at FIGHT CRC all the time. What if someone is under 45, doesn't have a family history, they want to be screened? I know a lot of EAO patients want the screening age to be lower. What's the rationale, where the screening age is where it is, and what would you recommend to somebody if they're having issues and want to be screened without a family history, and they're under the screening age? That's kind of a multiple question, there.

Fola May, MD:

Yeah. I mean, I would like to hear the panelists comment on this too. It's tricky, and I get it. I mean, I've met a lot of families who've lost family members in their 30s and their 40s, and they say to me all the time, "You lowered it to 45. We're really happy that you were involved in all the policy change, but it's not low enough." Right now, we don't have enough data to support at a population level that all Americans should be screened at 42, 43, 40, any number lower than 45. I do acknowledge, though, that obviously for some people, it would be beneficial if the screening age is lower, but the cost of doing that is impossible, and the number of gastroenterologists is probably also impossible for us to offer this service at 40 or 35. That's why we stick to 45, and we really try to make sure that everyone gets it at 45.

Fola May, MD:

What I do say to people, and I think David and Mark touched on this, when you're below 45, the key at that point is to not ignore symptoms, because the majority of cases and people under 45 are people who walked around with symptoms for a long time. What you can do if you are concerned under age 45, for you, family members, don't ignore blood in the stool, don't ignore new constipation or new diarrhea that doesn't go away. Don't ignore persistent abdominal pain. It's ignoring these symptoms and thinking that they're going to go away on their own, that they're nothing, and doing that for a year or two, that leads to a very late cancer diagnosis that we can't cure. I really focus on getting everyone screened at 45 and really being attuned to symptoms at ages before then, but I know that doesn't make everybody happy.

David Sheir:

Zac, I have a couple of things I want to say about that,

Zac Getty:

Please.

David Sheir:

Yeah, the first one is, if you have family history, which is an obvious answer, but I was able to successfully get my 26-year-old daughter to have a colonoscopy on the insurance plan.

Zac Getty:

Great.

David Sheir:

It took two or three times, but because of my history, she was worried and concerned. We were successful in getting the insurance company to acquiesce to us. At 26, she did have a cost-free colonoscopy, number one. I then have an 18-year-old daughter who may or may not be a hypochondriac, who had, quote, stomach issues. We don't know if it was anxiety, IBS, or whatever, and I'm not certainly suggesting anything, but based on her, quote, stomach issues, we were able to successfully get her a colonoscopy to look at her stomach issues, on the insurance plan.

David Sheir:

Lastly, certainly at a minimum, if you have no symptoms and you're under 45, which by the way, FIGHT CRC is still working on lowering that age through its lobbying efforts, but if you still want to have checked out and you have no symptoms, at a minimum take at least one of these FIT tests. You may have to pay fully out of the pocket for them. I don't know what the cost is, but it's certainly a heck of a lot less than a colonoscopy, and there is some comfort if you're able to take one of these FIT tests and it comes back negative and you have no symptoms. I'm not a doctor, again, but that certainly would give me comfort until such time as I reach that 45-year-old stage.

Zac Getty:

Sure. Thank you, David. Anything else? I've got a couple more questions here. This one's kind of for everyone on the panel, actually, and it was mentioned, I know briefly, by Shawna and David specifically with the tests they used, and there was this kind of stigma surrounding handling your feces and sending in your own tests. For everyone on the panel, do you have any ideas for fighting any stigmas associated with screening for colorectal cancer, or colorectal cancer as a whole? I'd love to hear from everyone, if you have any ideas.

David Sheir:

I mean, I'll take the stigma over death any day, by the way, first of all, number one. Number two, I think it's becoming more widely accepted because we are seeing people, unfortunately, in their 20s, in their 30s, in their 40s, getting colon cancer. You're seeing social media and TikTok and YouTube and Facebook and Instagram having more social media posts about it. I mean, if you go into, let's say for example, TikTok, and you just put in the search term colon or colon cancer or whatever, you'll see individuals as young as 20 or 30 or 40 doing these very fashionable informational reels, some of which have ostomy bags, which is the bag that you have to have, if you have a severe case, by the way, and need it. You don't always need one, but they're making it fashionable now. They're making it hip, and I think that the more awareness that the younger generation puts out there, we put out there as panelists and doctors and lobbyists, I think it's getting less stigmatized.

David Sheir:

I mean, I have it on my Facebook page and I'm forward-facing with clients all the time in my business, and everybody else, and I don't really care. At some point, you just reach a point in your life where you're like, "My health is more important than people's opinions," but I do think it's becoming a lot more widely accepted and less stigmatized.

Zac Getty:

Thank you, David.

Mark Moore:

Great point, David, because I feel that one of the biggest things is communicating. Communicating and advocating out there, because once I was diagnosed, I began to talk to a lot of my peers, a lot of my friends and just people in the neighborhood or in the community. When I was out, if I was speaking or if I was advocating, or just normal business, I would make sure that no matter what I was doing, I would always take time. I'd say, "Look, I want to also throw something in there. Have anybody taken a colonoscopy, or anybody looking to take it?" It's a reminder. You would think back before it really touched me, I probably would've said, "Oh, okay." I probably would've threw it off, but I understand how important it is, and once we started talking and we start to advocate and people start taking it seriously, I don't think this is as much as it used to. Now, like you said, social media have changed, because you're actually seeing people are not afraid to show, maybe wearing a bag, so they're not really ... You don't want to go through that if at all possible, and so my biggest thing is communicating.

Zac Getty:

Excellent. Thank you, Mark.

Shawna Brown:

Yeah, I agree. Communication is the key, and the more that we have the conversation, the more folks can get comfortable about even having it and accepting that we have to do this, right, and our health matters. You have to just think about it and say, "Do I matter?" Yes, you matter, and so you're going to follow through the process. I do believe, yes, social media has taken a turn where they are promoting it, and again, for myself in my community, I have taken that step to create a walk and educate our people, getting as many people as I can to be in the conversation, to educate. We're going to have fun with it because I think that we can have fun and educate at the same time, and save folks' lives. You matter. Take the test, just do it.

Zac Getty:

Thank you.

Fola May, MD:

I love it.

Zac Getty:

Yeah, that's amazing.

Fola May, MD:

I think the only thing I'll add is, I think that the panelists are spot on. I also just try to normalize words like butt and anus and stool, because I think even when people come to see me in the office sometimes, and I'm a gastroenterologist, all we do is talk about stool and farts and poop all day, but people are embarrassed to tell me their symptoms. It's like, these are medical conditions, these are problems. You shouldn't ignore them. We're used to talking about it and we want to help you, and we can make you feel better. We can make sure you don't have cancer that's causing these things. I think we need to,

even as young as little kids, normalize talking about having a bowel movement or having a poop, and we need to normalize talking about if your butt hurts, and having blood come out of your rectum. I just think that people are just so shocked when they hear those words sometimes, but generationally, we can change that if we become comfortable with the words.

David Sheir:

Yeah, one in three people will either be directly impacted or know somebody that's been impacted by cancer, so one in three people will either have cancer or know somebody very close to them that had cancer. I find that the stigma has gone away to a large extent. Especially, I find as I get older, my peer group starts to be more empathetic and sympathetic and doesn't really have those stigmas, when you get to be your 40s and your 50s and older.

Zac Getty:

Thank you, and I do want to point out that I think everyone that's taking the time to join this webinar today is doing their part actively to help reduce the stigma associated with screening and with colorectal cancer, so thank you to you all. I do want to be sensitive of everyone's time. I do have one more technical question that's come through here, and then I think I'll let everyone go. I would like to ask everyone, if you have questions that you didn't think of or if you think of something after the fact, after this webinar is over, please feel free to email me, zac@fightcrc.org, or info@fightcrc.org, and somebody will get back to you, address your questions to the best of our ability. The last question I have here is, what if you have a family history and your first colonoscopy is fine with no polyps? Do you still follow that 10-year follow-up interval?

Fola May, MD:

Oh, that's a really good question, because I didn't get the chance to mention that, so thank you. If you have a family history, a real family history, meaning mother, father, sister, brother, first degree is what we call that, not only do you screen early, so at age 40 or 10 years before the earliest family member, you also screen more often, and you also only screen with colonoscopy. Those people who fall into the bucket, and we think it's about 20% of people, you want to make sure that you screen at the earlier age, you get a colonoscopy as your screening test, and you have to get the colonoscopy every five years, not every 10 years. Those people we're just more vigilant in, and that's because their colorectal cancer risk is higher, as we mentioned. It gets a little trickier when it's a grandparent or a cousin, second or third degree family member. We don't treat those people the same as we treat someone who's got a first degree family member, so these rules that I just said about 40 or 10 years older, or younger, colonoscopy only, and every five years, really only account, are only followed by people who have a first degree family member.

Zac Getty:

All right, thank you very much. With that, I'm going to close out the webinar. I do want to give a huge, massive thank you to Dr. May, Shawna Brown, Mark Moore, David Scheir, for taking time out of your very, very busy schedules to join us for this hour today, share your stories with us, talk about some stuff that people don't necessarily want to talk about. I really, really appreciate it. Raising awareness for this, I think, is the most important thing we can do. Advocating for getting screened, everybody watching this, everybody watching the recording, everybody reading the transcripts, please go get screened if you can. Thank you all so much. I hope you have a great rest of your week, and for those of you that are joining us in Congress in DC this weekend, we will see you there. I do like to end every webinar with our mission

statement. FIGHT Colorectal Cancer's mission is we fight to cure colorectal cancer and serve as relentless champions of hope for all affected by this disease through informed patient support, impactful policy change, and breakthrough research endeavors. Thank you all again for everyone joining us. Thank you for everyone that joined us to watch. Like I said, please feel free to send any questions my way. Take care everyone. Good to see you.