

Speaker 1:

Good afternoon or good morning everyone. Thank you all for joining us today for our Save the Booties: Early Onset Colorectal Cancer webinar. My name is Zac Getty and I am the Disease Awareness Program Manager here at Fight CRC. 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 today, let me go through a couple of housekeeping items with everyone. We will have some time at the end of the webinar for general questions, but please feel free to use the Q&A panel on the right side of your screen to ask any questions that come up along the way. We'll do our best to address them at the end of the webinar.

This webinar is meant to educate as well as serve as a forum for you to ask your questions. So please don't be shy. We will do our absolute best to answer any and all questions that are asked during the webinar. We will have the recording of this webinar available on our site within the next few days. You will receive that direct link via email as soon as it is available if you have registered for the webinar and we'll also provide a transcript of a webinar on our site for those of you that would prefer to read the information discussed today. And we will also include the slide deck that is displayed today. Please feel free to tweet along with us. You can use the hashtag CRCWebinar.

Please remember to stop by our website at [fightcrc.org](http://fightcrc.org) to check out all of our patient and caregiver resources. This includes your guide in the Fight meetups, which are an online space to meet with other patients and caregivers that are held twice a month and touch on a variety of topics, but are also just a great place to find a sense of community. We also offer 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. We are also now hosting a monthly mega meetup, which addresses a specific and unique topic each month. Our next mega meetup is serving as a space for those who have lost their partner or spouse to colorectal cancer. It'll help or it'll serve as a place to connect with others and share your story. This will be hosted on Wednesday, September 25th at 7:30 p.m Eastern. You can RSVP for that in our Community of Champions app.

Pardon me. Real 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 substitutes for professional medical advice, diagnoses, or treatment. If you're 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 Colorectal Cancer never recommends or endorses any specific physicians products or treatments for any conditions. Okay, cool. With all of that out of the way, I would like to briefly introduce our panelists today. Joining us are Erika Bilger, the Fight CRC Director of Research Advocacy, and stage four colorectal cancer survivor, Danielle Ripley-Burgess, Fight CRC Vice President of Disease Awareness and Chief Storyteller, and also stage three survivor, and Andrea Dwyer, who is an advisor to Fight CRC from the Colorado University Anschutz School of Medicine. Thank you, the three of you for joining us today, taking time out your schedule. With that, I am going to hand it off to Danielle to introduce herself a little more in depth and get into the meat of this webinar.

Speaker 2:

Thank you, Zac, and thank you everyone for joining us. We're really excited. We've been planning this webinar for several months now, and the three of us are just really giddy to have you. Before we get too into the weeds though, we wanted to know who you guys are and who is joining us. We had over 100

people sign up register. This is obviously a very popular topic and we've pushed this out to the research community, the medical community, as well as the patient community. So Zac's going to put a poll up here in a second and would you guys mind filling that out and letting us know how would you classify yourself? And even if you fall in multiple of these, which one is probably your primary drive for being here today? We'll give you just a couple seconds to fill that out.

So while you guys are filling that out, I was going to introduce myself again. Like Zac said, I am Danielle Ripley-Burgess, and I'm our VP of Disease Awareness and here with two of my comrades who also have very personal connections to this disease like I do. And so before we got too into the weeds of some of the research and the science, I wanted to kick us off just with some stories. And so you guys know why this work is so personal to a lot of people on our team, but especially the three of us and how we are connected not only to colorectal cancer, but early onset colorectal cancer. So if you don't know my story, we don't have enough time for me to give you a play-by-play of the past 23 years. But let's just say the past two decades of my life have been under this umbrella of colorectal cancer.

I was a teenager when I was diagnosed. I was age 17, just a few weeks after my birthday. So I was newly into being 17 and at the time I was told this was unheard of. Nobody had ever seen somebody so young, a young adult. All the websites said this was happening to people grandma and grandpa's age. So as you can imagine, quite a shocker. This was in 2001. So sometimes I tell young kids, this is pre-9/11 stuff. So no smartphones, no social media. 9/11 hadn't happened. This is how long ago it was. Fortunately for me, we got me rushed into treatment very quickly. So I had a very aggressive treatment that was both chemo and radiation. Because of my age flagged genetic testing, so we quickly got that involved and just flash forward a little bit, what we've come to find out over the past two decades is that I do have Lynch syndrome, although I did not inherit it from my mom nor my dad.

Because of my Lynch syndrome diagnosis, I've also had to be very aggressive with my followups. It took a while to figure out I had Lynch. So I've actually had two other diagnoses since my initial diagnosis when I was 17. When I was 17, I was stage three. And then when I was 25, we found an early stage cancer that was stage one, and actually a little over a year ago now when I was 39, we found my third cancer, which was also stage one. We found that third cancer during a surgery for a permanent ileostomy. So I'm now an ileostomate. So that's just a little bit of my story, what I'm bringing to this.

I can speak to ostomies, I can speak to fertility. I'm an adoptive foster mom as a result of this. So that's definitely impacted our family planning. And a lot of what I get to do every day is to help create resources and tools and conversations like this webinar for all of you guys out there who are facing this at any age, but especially those of us on the call viscerally know what it's like to be young and face this. So that's what we wanted to bring to you guys today is just some community around what you're feeling and facing and also hopefully some hope around what work is being done. So with that, I'm going to pass it to Andi to tell us a little bit about your experience. Why is this a personal cause for you?

Speaker 3:

Great. Thanks, Danielle. So my mom was diagnosed with an early stage, which that's all she would really share about her diagnosis when she was 41. But what's interesting is we really didn't learn about her colorectal cancer stage one diagnosis until I was actually in my 30s and it was time for me to be screened. And I often look back, and maybe it's because I was in my late teens, early 20s at that point, it's so funny, I don't know why I thought she would've had bowel resection and been at home for a month, month and a half after a pretty invasive surgery. And it never dawned on me that it was colon cancer or that it was any sort of cancer at all. But looking back, I just realized maybe how naive many of us were about colorectal cancer, the disease. But what I've always remembered from that is that it was a really vulnerable place for my mom.

And I think there were maybe one or two people that she told internal, but she didn't talk about the disease, she didn't talk about her diagnosis even though she was sick and had symptoms for a long time. I think it always really struck me as someone who's very involved in research and very involved in all things cancer screening prevention and control. I mean, I had just started my career in cancer work and my mom still even at that point didn't share with me that she'd had a diagnosis. And so I really take a lot from that experience and really think about what it means to have a diagnosis for people and what it means for families. I did get my first screening in my mid-30s and I should have started earlier and I think my mom was really trying to stress, but what's interesting about my personal story is I think that it wasn't until I started really dedicating a lot of time to colon and rectal cancer that my mom actually told her story.

And working with Fight CRC was actually the first time she ever really talked about it. So naturally as you do is like you go ahead and just do something for an advocacy organization and tell thousands of people when you hadn't even told coworkers, you hadn't really told family. But I think it was really a good time for my mom to finally talk about what it meant. And I don't know if Danielle remembers, but it was a blog that my mom wrote at Mother's Day, and I think she shared a little bit about her signs, her symptoms, and then what she wanted other kids to know about her experience in terms of what she shared. And moreover, what she didn't share at the time of her diagnosis, which I always thought was exceptionally brave. So many of her coworkers, people in our small town, that's how they really learned about her diagnosis and where that was.

And I think it really started a lot of conversation as she's a healthcare provider as well. So based on my mom's diagnosis, I've had genetic testing. I have a VUS, so basically, as many of you know means basically there's probably something going on from a genetic or hereditary standpoint, but they're just not exactly sure what that means. So as a result, I'm screened every five years and that's something that I think I take very serious, I think about the idea of being a previvor and if you've had family members with cancer and advanced polyp, really understanding what your screening recommendations and guidelines are. But even with my experience at CU and all my experience in working with Fight CRC, it was interesting, because I even somewhat missed my surveillance guideline after having my baby and life got busy.

And I remember I woke up, I think it was like eight months ago, and I had this in front of my face and that was my GI doc says, "How many is that?" And I said, "Five." And he goes, "And how many years are we out?" And I said, "I think seven." And he goes, "How embarrassing would it be if you of all people..." So I still remember this five in my face, because life gets busy and we all get busy. And I would love to tell you that my brothers have been great about getting screened at the intervals, but I think the truth is, I mean it's hard and there's a lot, but my mom was young and she was very young and what it has meant for her, and I think part of the work I've been very involved in early in my career, it was around breast cancer and it was around... But so much of my work now I think because of my personal experiences is really around the why, the how, and let's do something about the things that we know.

Speaker 2:

Awesome. Andi, I think I could speak to, Erika, I'm curious too, it's hard to stay on top of this stuff even when you know why and the guidelines, I, adherence is hard for all of us, even when you're a previvor trying to ward off future cancer. So Erika, you want to share your story?

Speaker 4:

Yeah. Thanks, Andi. Thanks, Stevie. Thanks everybody for coming. I'm, as Zac said, a stage four survivor. Fun fact, Danielle and I were actually diagnosed just a few months apart. I was diagnosed late 2000 and

she was diagnosed in 2001. I clearly am much older than Danielle, but I was still young when I was diagnosed. I was 22 and a graduate student and had been having really just an accumulation of symptoms for a year, maybe two years, kind of hard to pin down and say, but by the time I sought care or help from a doctor, I probably had every symptom of colon cancer, but I didn't realize that. And even still, I didn't really put up any big radar, send off anybody's radar that I could have colon cancer. So once I was being seen by a physician, it was still quite a few months before I ended up seeing a gastroenterologist who ultimately did a colonoscopy and diagnosed me with metastatic colon cancer.

So being young when I was diagnosed, there was a lot of concern about my staging at stage four, and that kind of kicked off a lot of activity and I ended up actually leaving graduate school just temporarily, but I didn't really know if it would be temporary at the time. And seeking treatment at a comprehensive cancer center that was relatively close to my parents, still a three-hour drive, four-hour drive, but I had multiple surgeries. My cancer had spread to my liver, so I had a number of surgeries to remove cancer in my colon as well as on my liver, and then a couple different kinds of chemotherapy.

And after about, I would say a year and a half, I was finished with treatment and kind of sent off to live my life. And so being a young person diagnosed, I will say I wasn't a teenager, but I was barely an adult, if that makes sense. I was just starting to kind of fledge the nest even though I was living hundreds of miles from my parents and on my own, I hadn't really embraced full adulthood yet. So it was a very tenuous time to be diagnosed and then moved forward into adulthood and go quote, "live my life." Unlike Danielle, I've been fortunate not to have re-diagnosis, but I would echo that as a long-term survivor, you kind of live under this shadow or umbrella of cancer even if you're moving forward.

Speaker 2:

Yeah. Erika, I'm curious. I know how I felt. I think I shared for a long time, I described it as I was the unicorn in the oncology ward, so rare. Nobody ever seen it. Curious how you felt. Did it feel like you were rare or unusual or did you know other people in your situation?

Speaker 4:

Yeah, I think unicorn is the word I would use as well. I felt like a unicorn. In fact, I even had a physician call me a needle in a haystack at one point and being in treatment centers and in infusion room, I didn't see a lot of younger people, let alone young people who had been diagnosed with colon cancer. So that certainly exacerbated my feelings of being the only person. I wasn't even in a cancer center seeing other young people really at all. So definitely felt rare, definitely encountered that. Every single time I met a new nurse, a new doctor, people were just like, "What? I've never seen this. I've never heard of this. This is so unusual."

And I didn't have a real explanation for why I had been diagnosed with colon cancer so young and without any sort of clear family history or personal history, it came out of nowhere, that also I think exacerbated my feelings of this being really rare and feeling like I was literally the only person out there. Of course, I would come to learn that wasn't the case, but like you said, early 2000s, we were not connected. There was not social media like there is now. So even Googling searching, I don't even know if Google was a thing, even searching on the internet, there were no communities of young survivors for me to find that kind of connection or camaraderie.

So I think maybe this is a good spot. Zac, if you want to pull up some of our slide props here. I thought it would be a good time to just level set, what does this mean? We're here meeting about early onset disease and for those of us who are diagnosed young because of being outside of what people think of in terms of who's affected by colon cancer, those feelings of isolation, well, what do absolute numbers look like? What do the data actually show us about who is diagnosed and what's happening in the under

50 population in terms of colon colorectal cancer? So ACS and other organizations estimate there's somewhere around 153,000 people a year across all age groups diagnosed with CRC. I'm going to use CRC as a acronym for colorectal cancer. So of those 153,000 diagnosed a year, about 20,000 or so are under the age of 50.

So if you think about the number of people diagnosed under 50 out of the total population of people under 50 in the US, it's a low percentage, but in the context of 20,000 people or so a year being diagnosed under the age of 50, we've probably built up somewhere around hundreds of thousands of young survivors in the US alone. So why early onset disease is getting so much attention now is because of trends since the 1990s. So when we think about, or even looking at these figures, in the 50 and older categories, we're seeing incidence has declined in the last 30 to 40 years. But what's been really troubling and gotten the attention of researchers, clinicians, and others is that in the under 50 population, we're actually seeing an increase since the 1990s. Zac, if you wouldn't mind going to the next slide. And so another way to think about this and why it's so concerning is because what we've seen over this time period is essentially a doubling of incidents such that now somewhere like basically one in five patients diagnosed with colorectal cancer in the US are over the age of 55.

And now for even more context, colorectal cancer is the number one cause of death to cancer in men and number two for women. This is a trend that we're not seeing only in the United States. Zac, if you wouldn't mind go into our next slide. So just another figure just to show that in the global perspective we're seeing this trend as well. This is a figure pulled from Rebecca Siegel and colleagues work looking across the globe at different countries. And basically any bar you see moving to the right indicates that rates of incidence under 50 years old are increasing in that country. So colorectal cancer, while still relatively rare in the under-fifty population, is increasing and is predicted to continue increasing and showing to be a major factor in mortality rates in the under 50 population in the US and beyond.

Speaker 3:

Erika and Danielle, we talk about this, because I think Erika, you talked about the overall numbers and people are like, well, raw numbers as opposed to older people who get colorectal cancer or overall absolute numbers. And people keep saying you're the exception to the rule, the needle in the haystack. And I think those first grids that you shared, those are things that I think one of the things we have been talking about is, and I think we've been having these conversations since about 2015, '16, is these rates are growing. And I think the absolute numbers in the whole world of science and epidemiology and population health people will say, yeah, the overall. But I think the one thing I think I just want to really stress right now is that this trajectory is it's not slowing down and we know that screening rates are on the rise for people who are older.

And there's all of these sort of trends that show people who have interventions and who have all of these sort of factors, those rates may be going down, but for early in the young people left of 50, we know that these things... And so I think one of the things I think we really talk about is that whole idea of equitable care. We talk about screening, we talk about screening guidelines, we talk about the why. And I think that as the science moves forward, and we've had this conversation with many of our epidemiology partners, our science partners, is that I think that the dichotomy of early onset being left of 50 or right of 50, I know that conversation I think is even starting to change. We're starting to say, what's going on with colorectal cancer in people who are teens and 20s and 30s?

And as we move on, I think we'll start to really look at subset of populations and understanding. But I think one of the things is we really try to think through Fight CRC's work, University of Colorado Cancer Center, many of the academicians and scientists and medical providers is this isn't a blip on the screen, this is legit. And I think the most concerning thing is that the numbers are growing and I think we've all

talked about to a certain degree, we really don't know why. The other thing I think is really interesting on some level is, and I mean interesting in that what's going on is especially in breast and lung cancer, for early disease people who are younger than 50, we're seeing similar trends. There's something going on right now, but I don't think we can minimize this whole idea or the fact that the two of you are rare, because I think that sort of rare isn't becoming as rare as it once was.

I know that many of the folks that are on today fall into that category and some of the comments that were coming in. And so I just want to say that I think that can be really hard. And I know we've all talked about the mental health side of what does that mean when you're someone who's in this space and you're seen as an outlier? I mean, that's hard. I think it's really hard and we'll talk about causation and what we know and what we don't know and where the science is going.

But I just want to harken back, and I talked to Danielle and Erika about this that a couple of years ago we hosted a focus group with Fight CRC and so many young people who were diagnosed with this whole idea that, "I didn't think it could be me. I received this sort of a diagnosis." And the thing that really bothered me, and I know we're focusing a lot on mental health this month through Fight CRC, but this whole idea of shame and this whole idea of fear and shame and I should have known. I should have done more.

I should have paid attention. I should have used the dollars that I had for paying out of pocket for a \$4,000 colonoscopy, I should have used that instead of hanging out with my friends or buying ski equipment. It broke my heart. I'm thinking how are we in this situation? And I know our voices and our stories about this isn't just random anymore, it really is starting to gain ground. But this whole idea of the numbers and what it means for us and the interaction with the healthcare system and just larger that it's happening more and more. I mean, there's some big baggage as it relates to that. So I don't know what the two of you, but I really think back about all the conversations we've had about, Erika, to your point about the numbers, but sometimes even being a number and what that means as it relates to your disease and diagnosis. I mean, there's a lot of baggage with that.

Speaker 4:

Yeah, I agree. I mean, I think being seen as rare, which totally less rare now. I mean, I think physicians who at one point would've been like, I've never diagnosed CRC in someone under 50 would, I bet there aren't as many now as there used to be, they're seeing it more. But being rare doesn't negate the effects of what the disease means for the patient. And sometimes I felt like that was about all a physician had to offer me was, "Well, this is just really unusual." But that didn't help me with the nuances of what it meant to be a survivor and how do I decide what to prioritize with my finances or my limited finances as a early 20 something?

How do I reflect on the choices I made to maybe delay care? Which I had a lot of guilt about. I should have gone sooner. I should have brought this to a doctor's attention sooner. Or even just things like looking at what was identified at the time as being linked to or associated with colon cancer was really related to lifestyle and behavioral things and so there is a place for guilt and shame there as well. And I didn't see myself reflected in that, things like obesity or smoking or drinking, but certainly it planted this seed in my mind that I had done something to get cancer in the first place.

Speaker 3:

For sure.

Speaker 2:

Yeah, I can relate to that especially why didn't I speak up sooner? And so it's getting fuzzier the older I get. But I think I had pinpointed, I first saw blood in my stool, it's probably about my daughter's age now, so she's almost 14. So I think I was 14 or 15. I actually thought I'd started my period, just didn't know. And so I went through this whole process of trying to eliminate red foods from my diet and kind of this denial of I was even seeing blood in the first place and this went on for years. And so when it finally came to my diagnosis in my late teens, and as I've told my story over the years, people have said, "Ph my gosh, how were you bleeding for so long and you didn't say anything?" And it's just this reminder and it's like, could I go back and say something earlier and expedite the issue? For sure.

Was I even aware that this little menace of a health problem could be cancer? No. And even the words when my parents came up to tell me the doctor had called and the pathology was back from my biopsy during colonoscopy, they told me it came back malignant. And my first response was like, what does that mean? I learned about the large intestine in anatomy class. I didn't know the words, even colon and rectum. And so I think it's interesting, often when I share my story, I say ignorance is bliss. The older I get, the more I realize what I've gone through. I'm 40 now. A lot of people, if I was diagnosed today, I would still be considered an early age, a young adult. I'm 23 years into this. Now that I know, that I'm older, I realize why I used to get the stares and the looks.

Back then I just had no clue. And I guess being a teenager didn't really care. But I think when we talk about young adults and especially mental health, one thing I think we have to be careful of, and I know our teams at Fight CRC are sensitive to is just not assuming young adults know everything that older adults know. And cancer is not on our radar and the vocabulary is not on our radar. And the awareness, we're aware of our bodies, especially younger generations are more emotionally aware and mentally aware. That's improved even since I was younger. But young adults assuming that a symptom is going to be leading to cancer is not necessarily something I think is fair to expect. And so I think even our educational programs and our messaging toward younger communities needs to be sensitive to that, both validating the knowledge gap and also the emotional aspect of all of this. Andi, is that in line with what you're seeing and hearing too?

Speaker 3:

Yeah, I think we're starting, I mean, one of the things we worked on with Fight CRC for one of the early onset working groups is particularly watching for signs and symptoms and what's most likely colon and rectal cancer. And that was an analysis of the literature, what's already been in literature, and that's helping providers think about it, but I think we're starting to think patients. But what I thought was interesting in that sort of thing, we had a working group, we looked through all the literature, we looked at the signs and symptoms, what was most likely yielding a colon and rectal cancer diagnosis. And you're right, Danielle, was bleeding predominantly was one of the big... But we went through this process to identify those and saying, look, this is a big deal. What I thought was interesting is New York Times took that and just went gangbusters and they're like, "Hey, we hear about this increase. We don't know why, but here's something."

And I thought was interesting on some level it's like it was great when the New York Times and people are talking about what are those signs and symptoms, because I think a lot of times we're just talking about the raw data and Erika many of the trends you're talking about. But I almost feel like it was the press and everyone was hungry for what can we do about this and what can be on. And so part of it was provider facing. But what I love about these pieces is trying to say, look, blood in your stool when you are 23 can mean a lot of things, but this could be a smoking gun, man. How do we start having those conversations? Because I think so much of that discussion, so as we can, to your point, young people can start thinking about getting in touch with your body and understanding.

And I just want to go back because I think we've been talking with the National Cancer Institute and we've been talking to the DOD and we've been talking and they're like, the work you all have done and the colon and advocacy groups have done around early onset. This is happening in lung, this is happening in breasts, what are we going to do collectively for young people? What are we really thinking about? And I think it really kind of comes back to your point, Danielle, about when you're 17 and you see blood or you're 13, tell someone, talk about it.

Because I think if we see changes in our body, whether it's changes in a breast or how we feel or what it looks like or blood in the stool and changing, it's like about having a conversation that something may or may not feel right and regardless what age, it still needs to be discussed and it needs to really be elevated on some level. And I think as you guys were talking about that, I mean I've just been thinking a little bit about what is this message just to say it's something we got to at least keep on the radar.

Speaker 2:

One thing I wanted to add just to this conversation, so as I shared my story in the intro a little bit, so I have Lynch syndrome now, but I did not know that on day one. And so because of my young age, it set off the alarms and I did go through genetic counseling and genetic testing, but I tested as that VUS that Andi mentioned that she has. So genetic, it's unknown significance. So they were like, something's going on, but we really can't pinpoint what. So for a long time I was kind of in Erika's boat where I was a young patient, no family history, came out of nowhere, didn't fit the lifestyle causes for this. So for a long time I felt like just I had no idea what caused it and kind of maybe almost internalize some of that guilt and shame. We've been talking about 12 years in, I think I found out that I did have Lynch syndrome.

It was after my second diagnosis they sent in my test results again. That time it didn't come back like VUS again, but something was more suspicious. And so I changed my monitoring. I started getting colonoscopies every year and my medical team said, "Hey, we're going to treat you as if you have a genetic disease even though genetic testing isn't proving you do yet." So what happened was that the lab basically reclassified my variant and so enough families had tested, they were able to put it all together and I got these random reclassification alerts, which I've heard from genetic counselors in the past few years, this is actually common. I had no idea this could happen. That's also a message I tell any young person on this call who had genetic testing is it could change. You could get a call from your hospital any day and they say, "Hey, you had tested as a variant of unknown significance or you didn't have a genetic tie, but science has evolved and now we do know you have this."

So I will say now I have a cause for what's happening with me. Now I'm back to that needle in a haystack situation Erika mentioned where I'm the de novo patient. So my mom nor my dad have the mutation. So I am the first. I've heard it's incredibly rare. Most people can't or have never found or met the first person, but that is my story. I do think it helps with knowing what's behind mine as far as it is a genetic thing, but I think I also feel some survivor's guilt when it comes to it because I look at so many other fellow young patients and I want the same answers for them. I want the genetic test to not be unknown anymore. I want us to know more so we can do more because maybe more of it's genetic than we realize. I'm still evolving.

I have a second gene that's still sitting in the VUS. I had two at play. So one, we know something's going on, the second one we don't. And I'm like, there's so much we still don't know. So with that, I actually, Andi you can speak a lot more to this. I think we're getting on the topic of causation. I always laugh because we use big words with the research team. Etiology and causation. For folks who don't know science, it's kind of like what's behind us and why is it happening? One thing I will say that helps me deal with some of the anxiety I do face just on an ongoing basis, two things really. Therapy, which I really recommend to any young patient on the call, any caregiver and any provider seeing a young patient.



Going through therapy has really been beneficial and helped me even articulate this story and handle the emotions that have come up as I've processed.

The second thing that's really been helpful is for me to get involved in this organization. I've been around Fight CRC for about 12 years and when I first came in, I came in as a survivor sharing my story like a lot of you guys on the call and I didn't really know up from down. I had briefly shared my story through Colon Club, which I'll talk about here in a little bit. But when I started to learn what our research advocacy team did and the impact that this team was making and where Fight CRC was and the work we were doing, it was very healing to me, because I didn't feel like I had to fight for myself, because I saw how people were fighting for me.

And this was in a league beyond what I understood. I'm a communications marketing PR major. So lay language, easy to understand pretty things was my specialty. So I had a lot to learn when it came to this area, but it's actually given me a lot of peace and hope and kind of purpose and pain type stuff. So we've got some slides and I can't wait. I think Andi, you're going to unpack what you guys have been working on.

Speaker 3:

Yep. Sounds great. So Danielle and I laugh, because she makes fun of me over all of the different terms I drop on occasion.

Speaker 2:

Your fancy words.

Speaker 3:

My fancy words. So if I say modality at all, that's just specifically for Danielle, because we really get a kick out of each other on these teams. So as Danielle said, and I know Michael and others had comments about causation and what do we know. We're really going to be talking about when we talk about causation, and I think as Erika and Danielle both talked about is that on some level, some of us do know what's related to our diagnoses and many of us don't. And I think at least for the overall population, it's about 10 to 15% typically that we can see is connected to a genetic or hereditary marker and for young adults, I think that's pretty comparable.

So it means there's a whole lot of the pie that we just don't really know why it's caused beyond aging, which for our group that's not really relevant. So Zac, I'll have you go to the next slide, but I'm going to talk a little bit about this in broad strokes. And I think to Danielle's point, if folks are really interested in research advocacy and being an advocate for the science, learning more about the science and ways to be involved as a research advocate, please let us know because we do have a research training and support program, the RATS program through Fight CRC. I'll have Carly who I know is on today even share some of the links about where our work relevant to the research is housed. So if you really want to get down and dirty into this work, we can and we can talk about what that means.

But what I want to say is some of the factors that we know are related to early onset, but all colorectal cancer, our diet and obesity, and I think Erika touched on those, Danielle touched on those. High fiber fruit, vegetables, a really well-balanced with good quality meats and as little red meat as possible. Those are the kind of recommended guidelines that holds true. So I think if people are using a lot of processed foods, a lot of meat particularly, especially processed meat, those are things that come up. Obesity, aspirin/NSAID use and lack of use, family history, very sedentary lifestyle that often leads to looking at obesity as well as really looking at some of the issues that can be developed. And we know that diabetes

particularly has a connection to diet as well as looking at sedentary lifestyle. But the diabetes pathway though has specific implications for colorectal cancer.

We also know irritable bowel disease, as well as smoking. And so I think those are no surprise to anyone. Those are the things. But I think one of the things I think you heard Erika say is she didn't really fit this right. This isn't really many of the things. And so I think as we're starting to think a little bit about this trend and this trajectory in people who are left to 50, what do we know about some of the things that we think are novel or could be causing causation that haven't been always on that known risk factor side? And what I want to say is this is just some of the ideas. This is not an exhaustive list, because I think there's things we don't know. I think the things that I'm going to talk about on the right, the question is, are they working as a single agent or is it really in combination with a number of contextual elements?

And I think it's probably the latter. As we've heard from many of our investigators, and we've heard from folks, antibiotic use, sleep patterns, the microbiome and how your gut and your immune response really is connected to that, the possibility of vaccines, pesticides, really thinking about processed foods and additives, especially since the '70s and '80s, H. pylori, and then even infections like HPV. And so if you look at the right side, those are many of the things that are now coming into play in terms of the thinking about how would we study and what does this look like. But as Erika said, as we were talking about this, this number of people are growing, the people who are in the prime of their lives seeing the impact for young people, it's heartbreaking. There's a lot of emotional and there's a lot of real interest in looking at this because of really the impact in our society and these young folks.

But I think that number is growing. But the one sort of interesting flip side is in terms of doing studies around this sort of work is that to power a study in a really meaningful way, to be able to study these novel risk factors, it's going to take a lot of people. And so knowing that the numbers are relatively small-ish in comparison to other types of cancer or people who are older or people who have something that's more of a prevalent risk factor, knowing this sort of thing, that's why the causation piece is harder on some level.

And I did see some comments saying, where are we in looking at trials? Where are we looking in terms of research? Are we advocating for that? And the answer is yes. I'll have you go to the next slide. But in terms of really looking at some of what's happening here, one of the things I can say is since when I talked about that time point in around 2015 to 2018 when many of us have been talking about like, hey, this isn't a blip on the screen, one of the JAMA surgery articles was one of the first.

It really just was like, "Hey, we're doing some level of discussion about this." And that wasn't even super high profile at the time in 2015, 2016. But that's about the time I started really working with Fight CRC and saying, yeah, I mean this is happening. We're seeing in the data many of the advocates and many of the researchers. And what I want to say is that I will tell you more than anything else I've seen in my career, which is almost at 20 years now, the scientific, medical, and funding community have risen to the challenge. The NCI, DOD have put in funding looking at being responsive, holding convenings, really looking at what they're doing relevant to their funding mechanisms, their cohort studies designs and have been amazing. The office of the director, many of the folks that I've chatted with are all behind this work.

And I think that from bureaucratic and political agencies, this can be hard. And I will tell you the amount of energy that's being focused on how do we really let researchers know? How do we really provide funding? How does policy and the team at Fight CRC around policy, how are they talking about the stories and the impact? And much of the data that Erika and then the real experience that both have shared and I've shared, how do we move this? And I think what we're seeing now is the Cancer Grand Challenge, many of our international funding initiatives and the NCI, DOD, and many of the research

convenings are starting to talk about rowing in the same direction as a globe. So continents, countries, what are we going to really be doing? Because I think again, to that whole piece is that we are going to have to power studies and it's going to take real representation from many of the countries globally where we're seeing this impact.

It's not just the United States, it's really global phenomenon, especially in more developed countries. We're really starting to see this. So one of the things we've been doing with Fight CRC since about 2018, '19 is really hosting these convenings around what should we look? And so many of those risk factors on the right, we've been talking about how to study those at different time points in life with different sort of exposures, with different sort of models, with different sort of approaches. And I'll tell you with these sort of convening power that only I think very few in the world can do, and that's well-positioned advocacy organizations, we've gotten a lot of interest from industry, academia, the medical community as well as these funding communities.

And I will tell you, building off the three or four large convenings that Fight CRC has hosted, we've been partners with NCI as well as many other partner organizations, we're moving into a large-scale international discussion, even coming next summer in Barcelona and hoping to have again, global representation from over hundreds or at least 100 to 150 folks talking about what we're putting into play as a result to studying the known as well as unknown risk factors.

And what I'll say about this as just a teaser for this, and I think to the comments, it's about now doing things with what we know and about implementation science in this area and getting an actionable plan together. So many of our international colleagues as well as what's been funded through the Cancer Grand Challenge and others, there's a mechanism to start really implementing many of the suggested ideas and what we know. So I'm super stoked. There's so many things we could talk about relevant to this and what we know and what we don't know and where the science and what it fits. I would just use this as a teaser to say if this is the sort of thing that you are really interested in and really want to get with us as a survivor, as an advocate, as a family member, there's a space for you to be very much devoted.

But Fight CRC is really helping convene lead the kind of lead the way in terms of having discussion. But again, I just want to reiterate that it's not just about one country, it's not about one organization. It really is going to take many of us and many of the funders to be able to move this to study causation in a way that makes most sense. It won't happen overnight, but we really have to keep the pedal on the metal. So I would just invite you all in as we start to think through that. And again, reminding everyone, I think to both everybody's point today and even when I'm seeing, the stories and the impact, it makes the biggest difference. So even if you're not in it to win it from going to a policy briefing or becoming a trained research advocate, your story and what it means for you and the impact, that is still a huge and a invaluable contribution to the work. So I just want to reiterate that as well.

Speaker 2:

Andi, this is awesome and I hope everyone's encouraged. We're trying to give you guys a snapshot of so much that's going on, years worth of work, and the research team is just killing it with these conversations and they're really driving it. I do want everyone to know I am watching the clock. We've got about 10 minutes left on the webinar and a lot of questions and comments are coming in, so thank you. We will get to as many of these as we can, but I do want to address the comment I hear the most, not only when I share my story, not only when people come to Fight CRC wanting to do something, but when you guys share your stories like through our website and you have a message to Congress, you have message to the world, many of you talk about the guidelines for the screening age.

So talk about elephant in the room sometimes. So Andi, I'm going to lob this heavy question to you because many people in this community want to see it lower than 45. So you and Fight CRC were integral in even getting it from 50 to 45. So could you talk a couple things? One, what does it take to move a guideline? Help us know how monumental that is. And then two, thoughts on it going even lower in the future.

Speaker 3:

Yeah, absolutely. And I'll speak to this with slides, but probably in the interest of time, Danielle will probably just do some overview as well. So one of the things I just want to remind people is that the screening guidelines that have been updated, that started with the American Cancer Society in about 2018, '19. In 2021, those were largely adapted by the USPSTF. What does it take to move a guideline? And I will tell you, pretty much moving a mountain, when you talk about population based screening, they really do take into consideration population based and what's best overall. They don't take into consideration money, they don't take into consideration quality of life. They really just take into a consideration based on incidence data typically. So how many new diagnoses and what does that look like in terms of number of people diagnosed and what does that balance look like where we should start screening?

It's done based on model. And what I will tell you is that there's a lot of debate about whether modeling is the best approach, but truthfully right now, colon and rectal cancer don't have randomized control trials to really lean upon in the biggest way possible. So the modeling studies have been utilized with many throughout the world to think about what does it mean to basically change a guideline? And what I will tell you all is that from 50 and over, that was really I think where everyone considered still continuing on. But when new data that showed the uptick, particularly from 45 and 50 and then even younger, the numbers that were growing, those numbers were absolutely somewhat small, but they were enough to move this guideline in this CISNET modeling to 45. And I will tell you that is a very precise model. They talk really about the benefit of where to start going through a very dedicated process.

And again, at another time and place, we could talk about three hours about these models and we could talk about what it looks like. But essentially that was the decision to move to 45 is because particularly in that cohort, in that group of 45 to 50 where we were starting to see that amount, that's really what drove that. When people say, hey, I mean, I got to be honest with you, when I know my mom was diagnosed at 41, I was like, why don't we drop that back to 41? The truth is that initially or essentially balancing what it for the overall population of likelihood of receiving cancer as well as where those model fit, we can't arbitrarily change. It's not arbitrary. It has to be used using these specific sort of resources, these modeling studies, and really I think using sound approaches, and that's what the United States is using.

I mean, different countries use different approaches, but I'll tell you, Danielle, the likelihood of it moving from 45 to 40 right now, it's probably not happening. What I would tell you is that I think Fight CRC, many of the groups all throughout the country and world are really watching that. If we continue to see this uptick, as these models and it's time for modeling, I would see if the science is there much like it was from maybe 50 to 45 that the United States Preventative Services Task Force, the American Cancer Society, all the advocacy organizations would really look at what does it take to redo those models, making sure the most accurate data was utilized. Because here's a lot of energy behind watching this and people want to do the right thing. But the one thing I do want to point out is going to the next slide.

Part of the debate has largely been that if we, we'll go to the next one, Zac, I think it's like the pros and the cons. Next slide, next slide. I think there's a lot of, why is it so controversial? So even moving from 50

to 45 is a big thing, and the science was there, the data was there. But again, I think people really in the scientific and medical community say in the younger group, we don't have absolute implicit data from a randomized control trial. We also think that there's a discussion that on some level, even for those who are at higher risk regardless of age, that we're not going to have the infrastructure, we're not going to have the resources to screen adequately from 45 to 50. And then I think the balance is, is at the end of the day, the risk factors for colon and rectal cancer still do skew to older people because of aging and because of many of those risk factors we talked about.

So I want to just remind folks that I get it and I'm there. I live it. We all live it here. But one of the things is in terms of urgency is I think what we want to make sure is that we're getting good data. We're making sure that those are put into the models in an appropriate time. We're making sure to advocate for good science so that those move forward. But in terms of moving arbitrarily guidelines to teens or 20s or what have you, that isn't going to happen. And I will tell you, as someone who's worked in this field, it shouldn't happen, because there wouldn't be enough resources. And I think for many of the things we've talked about, the public health messaging to get 20-year-olds to screen for average risk, there's a lot really loaded with that. So I do think we have to take that into consideration.

But one of the things I just want to say is that there are a ton of folks who have genetic and hereditary conditions, signs and symptoms who don't get the screening. And if we use the surveillance guidelines, so not the USPSTF or ACS guidelines for the average, but for high-risk populations, those are already out there. So those guidelines, you remember that five in my face? That had to happen every five years, and I should have started screening well below that 45 mark. I have to meet those standards. We have to meet those surveillance guidelines. Paying attention to signs and symptoms, there are workups. And I think that's the one thing I just want to note is that if you are at high risk, increased risk cancer, even adenomatous polyps, there's guidelines that we should start paying attention to and that will make a huge dent in the number of people who receive a colorectal cancer diagnosis young in the future.

Speaker 2:

That's awesome. Thank you, Andi. Those are hard words to say. I know that's not what a lot of people want to hear, but it is our stance and Zac, before you jump in with some Q&A, I'm curious, Erika, your response to that, because you're sitting here 20-plus year survivor. I have Lynch syndrome now, so I'm in a different bracket, so to say. So I've got the genetic thing. But for people who can empathize with you, 20-plus year, 20-year-old stage four. Hearing this about screening and screening guidelines, I guess, what would your encouragement be to people who can empathize with you and really don't love to hear, don't like what Andi just said.

Speaker 4:

I know, I mean, I think Andi is addressing something that being in this sphere for two decades comes up all the time in conversation. We need to lower the screening, lower the screening. And I think Andi did a really good job of trying to illustrate that just opening up colonoscopy coverage for everybody under the age of 50 doesn't really get or target the people who really need the colonoscopies. And that's the lens through which I can, even as a survivor, but also as a researcher and scientist, I can view this problem, if you will, through that lens. That at the end of the day, we want to get people who have diseased colons screened. And so we're going to, as an organization, me as a person out in the street every day, I'm going to toe that line that if you have a family history, I mean, there are all of these guidelines for people who are categorized as high risk that we also need to bang that drum.

If you have a family, I'm thinking about my own children who have two parents who've had colon cancer and their recommendation, their guideline is to be screened 10 years prior to when the youngest of us

who was me was diagnosed. So my children already know they're going to start being screened for colon cancer around being a preteen, 12 years old or so. So really I can totally understand, because even my personal story, but when I went to the doctor and I told them I had blood in my stool, nobody was overly concerned. But as I kind of ticked through the checklist, eliminating the low-hanging fruit, and it became clear that colonoscopy was the next step, I did do it. And I will admit, somebody kind of asked in the chat about resistance to colonoscopy. Yeah, it sucks. And I probably delayed seeking help because I was afraid I would have to have a colonoscopy.

I had a roommate in college who had Crohn's disease, and so I had seen kind of what she went through and I was scared of that myself. Of course, eventually my symptoms were so strong I was desperate for help. But yeah, I can totally understand why it doesn't feel good to hear the reality of the screening landscape and what that means for thinking about the bigger, the wider population. But when you think of what it could mean, I mean, I would just say run it the other way. Imagine that. I mean, what is the right age? Danielle, you were 17. I mean, what is the right age? We could always miss people and there's risk associated with having colonoscopies. So there's a lot of things that have to be considered beyond just making sure we catch everybody's disease. We really want to focus on those that need to be screened the most and making sure that they get that screening.

Speaker 2:

Yeah, totally agree with that. So to wrap us up, Zac popped back on. Do you guys have a few more minutes? We had some Q&A, but just to wrap this up, we still have several of you. I see you live, so we'll answer your questions as well as we can. But one push I'm going to make, if anybody's watching this and you're just like, "I have to do something. What can we do together?" This is just a big old invitation to join us at Fight CRC. And like I said, joining this has helped me feel like I'm part of something bigger and my story is part of something bigger, my energy, my money, my talents. And so we have a space for everybody here at Fight CRC. And one of the easiest ways to get involved is by sharing your story. And I told you guys I'd mentioned Colon Club later on.

So if you're especially interested in early onset colorectal cancer, Fight CRC and this small little grassroots organization called the Colon Club merged about a year or two ago, that is actually how Erika and I met, we were both involved in the Colon Club. Shout out to Molly McMaster who really pioneered this movement 20 years ago. She was also in her 20s diagnosed and realized that she was hearing the same things talking about today and said, "I'm going to raise awareness of this. This shouldn't be happening." So she formed this organization, she and a woman named Hannah. And the Colon Club for two decades has really helped a lot of us find each other. And that has now transitioned to be kind of under the Fight CRC umbrella.

But we are committed to continuing to have a space for all of you young people who've been diagnosed and maybe you're still young, maybe you're cool and hip and having your Brat summer and you've got your neon nails and you're in your 20s and maybe you're like Erika and I and you've aged out of AYA and you still think like a young person, but you're having gray hairs dyed every six weeks. So wherever you find yourself, were here for you and I hope you do come share your story with us and get involved in a lot of our efforts. So because you registered for this webinar today, you are one of the privileged people on our email list, so please don't unsubscribe, look for our messages and we'll let you know how we can get you engaged. Zac, back to you.

Speaker 1:

Thank you. Thank you everyone for sharing. So I'm going to try to get through a couple of these questions. We've got some good questions here. I don't know that we'll have time to get to everyone,

but I'm just going to start reading them off. So I'm going to go in the order that they came in. Are there any studies of the number of patients diagnosed between 45 and 49 since the change of screening guidelines in the US? Are there more people finding out at an earlier stage?

Speaker 3:

I can take that one. I do know right now that the uptake on the overall guideline from 45 to 50 is about 20%. So we do know on some level that it takes some time for guidelines to really take hold. I think that I would have to... That's a really good question. I do think we hosted a meeting in December that talked a little bit about what we do and don't know from this population right now. And Zac, I'd be happy to follow up on that, because I think there might be some preliminary pieces. What I'll tell you though is when guidelines are changed, not everyone 45 ran out and got screened. So we know that it's probably going to take five to 10 years for this to really catch on. So in terms of being able to say something about more of the folks, that might take a little bit of time, but it's a really great question. And I do think that Aasma who presented had a little bit of that preliminary [inaudible 01:04:50]. Let me check in that and we can put that back out.

Speaker 1:

All right, thank you. So directed at Danielle, Erika, and Andi too, since your mom was diagnosed at a young age with all of you being survivors, do you think the science is lagging behind the reality of what is happening in the real world?

Speaker 4:

That's always the case to some degree. We have that hindsight vantage point of looking back now on the curves on that far left panel I showed in the first slide. And so yes, I mean, I think a lot of the things that Andi spoke to that Fight CRC is involved with and engaged with, now that there are the data, it gives us really ammunition to fight and advocate for these things that we're talking about, screening recommendations all the way to causation identification.

Speaker 1:

Awesome. Thank you.

Speaker 2:

One thing I'll also offer the other side of that coin where as somebody who did have a gene reclassified, it did feel like I'm in the midst of science innovation because it was like, oh yeah, this is happening all the time and I didn't just have to sit on the unknown. And so I guess it's a plea too to don't discount the genetic side of this and continue to talk to your genetic counselors and make sure your blood work is up-to-date, you're on file, your stuff has been sent to a lab that would reclassify a gene, because sometimes I think there is a lot happening. It's just what does that bridge between what's happening maybe in the lab or in the research spaces and connecting it to the patients, that can also take some time, translating it to real life patient, how it can impact every day. But I was encouraged by that. So-

Speaker 3:

Yeah, and-

Speaker 2:

[inaudible 01:06:49] Another perspective.

Speaker 3:

I think what you're both saying is totally true, that it feels like it's already happening by the time you study it. It's already got a lead time and all these sort of things we know. But I will tell you out of all the things I've worked on in my career, this is probably the thing that's moving the fastest and I see innovation in screening, I know someone mentioned that. I see innovation in, Danielle, like you're talking about really what we're looking at in the genetic and hereditary sphere. We're looking at all the things, even things like early onset clinics that are actually popping up and becoming more part of mainstay. We have a ways to go. And I think you're right, Erika, we are always behind. But I will tell you this is the one area in medicine research and public health that I actually have been encouraged by. So we've got some work to do, but I think pedal's on the metal.

Speaker 1:

Awesome, thank you. So here's a thank you for highlighting these stories and an acknowledgement that the bottom line is that EAO patients are busy with their life so symptoms and timing of screening and making appointments is hard to get done on top of everything else that's going on. Any suggestions or solutions that you relay to help people know to listen to their bodies if they think something is going wrong?

Speaker 2:

Accountability. If you know... I mean, so many things. So find a buddy. Like Andi had accountability in her doctor who's waving the hand in her face. My parents and my friends would help me stay on top of it. I also think encouraging anybody here who's a parent or grandparent, keeping these open dialogues about bodies and body issues is really important. Because I do think it can start there with conversations at home and if you have a family who won't talk about poop or pee or periods or stuff like that, then it's going to be harder for young adults to open up because they're going to feel that shame. But if they have spaces where it's just every day where you talk about things happening with your body and it's normal and natural, admittedly this is a generational shift from even several decades ago, they didn't openly talk about it, but that's a suggestion of just how to get young adults to speak up.

Speaker 1:

Thank you. Andi, a specific question on your risk factors slide, you had novel risk factors and you had vaccines listed under there. Have any specific vaccines been implicated in this early age onset?

Speaker 3:

No. Let me just say this. I think what people are talking about are particularly... Let me just say this. I think for life course vaccines, particularly as it relates to children in infancy to looking at the data that I've seen mostly is sort of like time course of when vaccines are given on some level. And it's looking at mostly kids who are really young and understanding on some level if there's some connection based on life course. I haven't seen any called out specific that I feel comfortable on some level kind of saying things. I hate that that's on the slide on some level. I'm just going to be honest because I worry what is the backlash of what does that mean for people as it relates to this work? But I think if there's something there, we have to really deal with it, what that is.

I will tell you, and again I didn't get into the whole thing, but exposures. So there's a lot of discussion about even in utero, so before you were born, but your host who's carrying you, also known as your



mother, what's happening with you at that point? Because it's about cellular differentiation and what happens to cells at different time points and when do those exposures with that whole idea that many of the cells are a little bit more vulnerable for what's happening in the differentiation process. And so what I will say, Zac, is that on some level, the vaccine discussion that I've heard about are really based on those exposures and time points in life kind of holistically right now.

Speaker 1:

All right, thank you. We've got two more, if you've got another minute or two, I think we can get both these done and then close out. I want to be respectful of everyone's time. Question generally, how can we create more conversations within the medical space regarding the dismissal of symptoms in young adults?

Speaker 3:

New York Times is helpful. There's been a lot of discussion there. I will say this about providers, and I think this is one of the things Fight CRC is working towards is also how do we work with the primary care providers moving forward to really talk about what is it that we can do? There's a lot of us in the advocacy policy, research, the space. We don't all deal with folks that are on the frontline, nor is it probably a place where we always should be detailing. But one of the things that we've started in the work I do with Fight CRC as well as CU is having more conversations about getting in front of the people who make decisions about primary care, make decisions about how patients are from health promotion to primary prevention to health and behavior. We're having more conversations about like, look, this is a big deal.

How can we partner? How can we use these patient stories? How can we do these sort of things? And Danielle and I are working on a module right now with our screening program in Colorado where we're using survivor stories to talk about what was your experience? What happened? What do you want the primary care team and navigators to know about this as you get into the work? And so Zac, what I would say is I think we have a real opportunity on the training and on the side of working with providers through their normal course of how they're educated and keep things on the radar. But I think also the voice of the patients and getting big headlines, it never hurts.

Speaker 2:

I just want to add to that, a lot of Zac and I's work is focused on patient and provider education. So we're kind of strategies to reach out to those primary care doctors Andi mentioned. And the other thing I think all patients need to remember is similar to members of Congress, ultimately they work for us. Ultimately your doctor, you're most likely paying to go see this doctor. And you have to remember that. I know it's different. I know it's healthcare. I know sometimes you might be in a rural setting and your options are limited, but you have a choice in who your doctor is unless you're admitted to the hospital and you can't control the hospitalist coming through. So don't feel bad to shop around, get a second opinion. We've got a provider finder on our website. If you're looking for a GI or an oncologist, radiation, surgeon, we've got provider finder that we can help you find them based on your zip code. But remember there is definitely choice in this. And so if your doctor won't listen to you, I would say start shopping for one who will.

Speaker 1:

Thank you. All right, last one. And this one kind of is a nice bow tie on this whole topic I feel like. Can you address the matter of maintaining well-being and longevity for young people diagnosed and treated with colorectal cancer?

Speaker 2:

Erika, I'll let you take this one.

Speaker 4:

Thanks for the punt. No. I mean, I actually think that's a great question and I have, in a way, the luxury of two decades of thinking about that for myself and my family now. I think for me, I'll just speak to what has been helpful to me personally. And that has been first and foremost a sense of community and this camaraderie that I have with Danielle and a few other survivors in my life. I mean, Danielle, we have lived through, we didn't know each other when we were diagnosed, but we have lived life in the last, what, 15 years of knowing each other. We've built families, I've been divorced, married again. I mean, we have been through it.

Speaker 2:

We've been through some life, adoption-

Speaker 4:

Exactly.

Speaker 2:

Moving, career change.

Speaker 4:

Exactly. Our family building stories, job changes, the whole, a lot of things. And as a young survivor, yeah, that's under, again, to kind of tie back to what I said earlier, it's kind of under this umbrella of colon cancer being a part of my life. And I try not to make cancer the focus of my life despite my work now, but having that camaraderie has been really helpful. And then I think some other things that would be applicable to all people, finding purpose, having meaningful relationships even outside of a colon cancer community or a disease community. Taking time for myself, focusing on my health. One thing that maybe I could have talked about was what this has meant for me personally is that I do really prioritize my own well-being. And sometimes I'm kind of seen as being selfish and unapologetic about it. But I do care a lot about getting good sleep. I do care a lot about stress and how I manage that. So taking care of yourself. I mean, there's no magic pill that we have right now to cure any of our ailments or any of our types of cancer. So it's like you have to do what you can and really ask yourself what's important to you and just live into that. I have a very close and wise person in my life, actually my husband, who's advice has been, "Put your head down, get through your treatment, and then live your life." Focus on what you love, focus on what's important to you. Focus on the people in your life that you love. Fight like hell. That's what we're doing here. We're fighting. But I think it's important to recognize you also really need to lean into the things that bring you joy in life.

Speaker 1:

Awesome. Thank you so much. And I think that's a perfect way to wrap this up. I really appreciate everyone sharing their story. Erika, Danielle, Andi, thank you so much for taking time out of your day to join us for this admittedly extended webinar. So I think it's awesome we've had so much participation and so many questions come through. I do want to take a second to share that we actually do produce a brochure specific to young adults in colorectal cancer and addresses some of the unique challenges that young adults face and experience when they are faced with a CRC diagnosis. So you can find this resource in all of our resources at [fightcolorectalcancer.org](http://fightcolorectalcancer.org) or [shop.fightcrc.org](http://shop.fightcrc.org).

And I'd also like to encourage everyone on this webinar today, there is an opportunity to continue this conversation, join us and Community of Champions, join a webinar or a meetup that we host twice a month. Share your story on our website. We've got a lot of different opportunities for you to get involved. Join us at an advocacy event like Call-on Congress in March in Washington, DC. It doesn't have to stop with this webinar and it doesn't need to end here. We are working on this all day every day, and we'd love to have your participation.

So download the Community of Champions app in the Google Play Store or the app store, or you can use it online. Join us at [fightcrc.org](http://fightcrc.org), share your story, get involved and keep working with us as we work to put an end to this. So thank you to everyone, again, for attending this webinar. Thank you to Erika, Danielle, and Andi for being panelists and donating their time. I like to end every webinar with our mission statement. We are Fight Colorectal Cancer. 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. Thanks for joining us. I think this has been a really great event. So thank you everyone, and we'll see you next time. Take care.