Mark Masselli (00:04)
The Colorectal Cancer Alliance says too many of our friends and family members are dying from colorectal cancer, the second deadliest cancer in the us. They're working to end colon and rectal cancers within our lifetime.

Michael Sapienza (00:18)
We need to figure out why it's happening so that everybody else, whether they're the youngest patient I met, 14 or 44, can also have the treatments that they need to be able to stop this in its tracks.

Margaret Flinter (00:33)
Our guest is the CEO of the Colorectal Cancer Alliance, Michael Sapienza.

Michael (00:39)
You know, if Ryan Reynolds doesn't get you to do it, or Dak Prescott from the Dallas Cowboys, we're gonna keep sending more people out with those messages that, you know, you can save your life, you can save your family members' lives.

Margaret (00:51)
And this is Conversations on Healthcare.

Mark (01:04)
Well, Michael, welcome to Conversations on Healthcare.

Michael (01:07)
Well, thank you. I appreciate you having me.

Mark (01:09)
Absolutely. You know, your organization says colorectal cancer is less known and less funded than other deadly cancers. Why is this, and, and what is your nonprofit doing about it?

Michael (01:20)
Yeah, absolutely. Well, your, your, listeners may or may not know, but unfortunately, colorectal cancer is the second leading cause of cancer related deaths in the United States only behind lung cancer. And unfortunately because of, in my opinion, stigma, lack of funding, et cetera, it, it, it isn't as well known as other cancers like breast cancer, leukemia, lymphoma, prostate, et cetera. And so what is the Alliance doing to, you know, counteract this one? We have this huge project called Project Cure, CRC, which is a hundred million dollars commitment to ending colorectal cancer in our lifetime. So, funding, you know, research directly to scientists and folks all across the country, just in six months, we've given out about $12.5 million to 24 projects across the country. And then in addition, from an early detection and screening perspective, we have what's called Lead from Behind. So it's a partnership with Ryan Reynolds and his, his, marketing agency maximum effort to really get the word out. We partner with him and Dak Prescott and others, to make sure people will get screened for the disease.

Margaret (02:32)
Well, Michael, I think really, true to all cancers, people have their image, what they've heard, what they've seen, what they've experienced in the family. They think colon cancer, they think ‘ugh’, they think colostomy, they think, deadly, deadly thoughts. But we'd like to give you a chance to talk about some of the initiatives you're funding, that really might be breakthroughs for us. Maybe tell us what CRISPR technology, something we've talked about on the show in relationship to other things might have to offer in the colorectal cancer space.

Michael (03:02)
Yeah, so if you think right now in terms of the overall survival for colorectal cancer, if it's diagnosed late stage, so let's just say metastatic or stage four, it's about 13% on average that you would, a patient would live five years or longer. If you compare that to breast cancer, we're at about 36, 38%, five-year metastatic survival rate. The things that I think, and that the alliance believes that are on kind of like the cutting edge, are one, targeted therapies. So whether we're talking about making sure we, you, we screen every single patient for their biomarkers, so BRAF, KRAS or HER2, what your MSS status, which may make you eligible for immunotherapy or not. So all those targeted agents and the biomarker pieces are so, so incredibly important. And then I would say from a what is on the horizon, vaccines or vaccine combinations, combination immunotherapy treatment. So only about 5% of patients in the colorectal cancer space will respond to

immunotherapy. But we're starting to see this glimmer, this glimmer of hope in what we say the other 95% or the MSS microsatellite stable group, where we have a couple combination immunotherapy treatments that are starting to work in a small subset of patients. If that would happen, it would be unbelievable. And then there's another, you know, group I would say CAR T til cell therapy treatments that are also starting to see some small, some, some small promise. So yeah, I mean, I, I, I think really the answer is additional funding, additional resources going into it, but also really changing what information do we need to get more targets in colorectal cancer and faster.

Mark (05:02)
Well, I, I know we're gonna get into the funding, part a little later, but I'd really love, your marketing team, leading from behind. Love that. But you also, part of the work includes something called Case buy, which is an interesting name. So maybe, this is, an initiative as I understand it, to test multiple therapies simultaneously. So tell our listeners more about that, Michael.

Michael (05:28)
Sure, Sure. So, we need more therapies and we need them quicker, and we need 'em in a patient's arms quicker because they wanna live longer. It's very simple. And case buy is actually, it's a derivative of, or the next generation of what's called I spy. So if you're in the breast cancer world, there's a woman, an amazing doctor, her name is Dr. Laura Erman at the University of Cal, California. San Francisco, who 15 years ago started I spy. So I SPY is equating to breast cancer. They've tripled overall survival through 45 sites across the country that allow patients to get onto clinical trials, uses Bayesian statistics to determine which arm they're on, and they fail fast or they succeed fast to be able to then go on to the next treatment or prove out, especially in the neoadjuvant setting. So before surgery setting, how well these, these different agents are doing. So we are in the process right now of building that closet, or as I say, the protocol, I call the protocol the closet. Mm-hmm. To be able to determine which hangers or which arms we're gonna have, of the, of that trial. We, we really do want to have a neoadjuvant, which is before surgery. We also, because there are so few treatments in the refractory setting, meaning the late line setting of metastatic, we also need to have additional, places encased by to make sure that we can plug those in. And then you've probably heard of the CT DNA space, meaning looking for circulating tumor within your blood, and hopefully that eventually will be a marker, just like, you know, a clean scan would be, or a negative, CEA test. So we're looking at all of those. We will have the protocol done within two weeks. We will be gathering in Chicago at a really, really important meeting, and we hope to have our first trial up by September, to be between September and October of this year, which is incredibly exciting for the colorectal cancer community as a whole.

Margaret (07:34)
Michael Colorectal, cancer we know is projected to become the deadliest cancer among people under 50 by 2030, with rates of new diagnoses climbing in this age group. I think this has been out there for the last few years, though patterns, may change in terms of screening, but there's some theories about why this is happening. So what do you and your colleagues say?

Michael (07:57)
Yeah, thank you. You know, the first patient I met, my mom unfortunately, died of this disease in Mother's Day 2009. Oh, the first person, thank you. Sorry. The first person that I met after she passed away was a woman, and her name was Jen Bogle. She was 33 years old, had a son, Rocco. And I was like, this is crazy. You know, how can all of these, the second patient was a 29-year-old, just so you know. And so this phenomenon or epidemic, as we call it, young onset colorectal cancer, has been going on for a while, but we don't know why. We really don't know why. But here are some of the things that we are starting to look at. One is, is it we're using too much antibacterial soap? Are we taking too many prescriptions and antibiotics? Are we not playing in the dirt as much as we should? Are we living in places that may be, you know, causing, additional, cancers? Are we using products that have microplastics? Are we drinking more soda or sugary based drinks versus, you know, milk or vitamin C and vitamin D based drinks? So there's so many different things that could be changing what we call our microbiome, right? It's like our gut and the gut gut health. And as those things change, there is now evidence that says you could be, you could be less able to protect yourselves from polyps growing within your colon, where that microbiome is. So, you know, we were one of the groups that was instrumental with the American Cancer Society to lower the screening age to 45. Mm-hmm. I'll say that again. Screening age 45. And now we need to figure out why it's happening so that everybody else, whether they're the youngest patient I met 14 or 44, can also have the treatments that they need to be able to stop this in its tracks.

Mark (09:56)
Mm-hmm. I, you know, you said, just a moment ago, maybe we're not playing the dirt enough, and I just was following the news on the spaceship where they're, catching more diseases because there's not enough dirt up there or things that, build up immunity. I'm wondering, and going back to your first question where you say, you know, lung cancer is number one, and colorectal cancer is number two, lung cancer, you sort of know maybe don't smoke, and that's probably the biggest preventive. What, what's the biggest preventative on the colorectal side that people should be thinking about? Is it diet? Is it…

Michael (10:32)
Yeah, it's a good question. First I wanna say about the lung cancer piece, unfortunately, the number or percentage of non-smokers that are getting lung cancer is continuing to increase. Wow. The number of people that are smokers slash Mount Peter get lung cancer, smokers are decreasing. It's very, very interesting. Mm-hmm. But for colorectal cancer, it's, you know, it's the sum of the usual things. So let's just say number one, a diet high in fiber, fruits and vegetables and whole grains, very, very important. Very important. So in other words, if you have a plate and it's all beige and you have no color in it, that's a problem. That is a problem, especially if it's day after day after day. Obviously exercise is really important. A diet low in alcohol consumption, no smoking. And then one of the biggest ones that's been talked about for years is a diet low in red and processed meats doesn't mean you can't have that steak every once in a while if you want it, or a processed meat every once in a while. It's just those things can't be your main diet. They cannot be, it's, it will put you obviously at risk for heart disease and other things, but it also significantly increases your risk for colorectal cancer.

Margaret (11:45)
Well, four years ago, it seems like longer, but four years ago, the US Preventative Services Task Force recommended that people begin that colorectal cancer screening at age 45 rather than 50, which is we said earlier, was the, previous recommendation, disappointing. There's, studies that show JAMA had a study that there's been a very small increase in screenings among younger people. And I think that that increase was primarily seen among people with higher incomes and perhaps higher education levels. So I'm sure this is very much on your agenda. How do we get the word out to all the 45 year olds about the need for this screening?

Michael (12:25)
Yeah, so I sit on the, the steering committee of the National Colorectal Cancer Roundtable, and every year they come and then we talk about what the percentage of people at different age groups is in terms of getting screened. And I will just say this, my mom died at 58 years old, and she had never had her screening. She was diagnosed at 56. So what I will just say, just to to everybody is now is the, the new age, the 45 is the new 50, as we say. Mm-hmm. And we are doing a ton to make sure that the general public knows this. So, you talked about the lead, we talked about lead from behind. You know, if Ryan Reynolds doesn't get you to do it, or Dak Prescott from the Dallas Cowboys, we're gonna keep sending more people out with those messages that, you know, you can save your life, you can save your family members' lives. But yeah, the screening rate bet, from 45 to 49 is only about 25% of that at risk group. And so we've got a lot of work to do because we still, the 50 to 56-year-old group is still at about 47%, which is well, well, well below where breast cancer is at about 80% of people that are getting screened. So, I, I can't emphasize enough. I've been to way too many funerals of people that are between 45 and 49. And it, it is obviously something that will save your life.

Cologuard Video with Dak Prescott and Ryan Reynolds (13:52)
As a professional quarterback, I get a lot of s**t Decisiveness in the red, the most overrated quarterback get More turnover sale. And I get it. When you're not a fan of something on, it can make you feel good. But what if I told you that now it can do some good too? Let me show you how. First, if you're 45 or older, talk to your doctor about getting screened for colon cancer. Then if you're prescribed a home screening kit like this, grab the sample collection container and place a sticker of something you want to shoot on, right on the underside, not a fan of marine life. Slap it on, have issues with old time prospectors. Boom, it works with anything from colors to large American predatory birds. Then follow the instructions on collecting and shipping your sample. Here we go. And in about two weeks, you'll have the results. It's that easy to get screened for colon cancer and make your feelings abundantly clear. So talk to your doctor today. Home screening kits like Cologuard are for people 45 or older of average risk, not for high-risk people like Dak. Dak actually wouldn't use a home test kit, but he's so committed to preventing people from getting colon cancer that he agreed to star on this video we wrote for him without any concern for his safety. I definitely deserve that visit lead from behind.org to get more information and some stickers we made.

Mark (15:17)
I think you know the answer to this, because unlike most cancers, colorectal cancer is often preventable with screening and highly treatable when detected. But you have a survey that really shows the troubling reality that people would just about do anything rather than getting a colorectal cancer screening. Were you surprised by these findings and, tell us what they, mean for your efforts?

Michael (15:40)
Yeah, absolutely. So I think the main stat was that 85% of people would rather do their taxes than get a colonoscopy. I mean, I think it means a couple things. One, we need to do a better job of talking to the public about the barriers, right? So saying, you know, why does a person not wanna do a colonoscopy? Well, maybe the prep, it may be time off work. Well, guess what? There are are other tests that are very effective, rated very well by the United States Preventative Services task force that can be done in the comfort of your own home. Right? You know, no prep, you don't have to take a day off of work. And as long as you are not high risk or have a family history to the disease, then you can do those tests. Now, granted, the FIT test or the Cologuard test have to be done more frequently. So your fit test every year, your Cologuard every three years, rather than if you get a colonoscopy, right? It's depending on if they find polyps, sonata, it could be that you don't have to have it again for 10 years. And then the most important thing that I always tell people is if we think about what we are doing in terms of these non-invasive or at-home stool tests, that if they're positive people need to go back in to get a colonoscopy. Doesn't mean you have colon cancer. It doesn't mean you have colorectal cancer, but it is the, the, the screening is only completed once you've had that follow up colonoscopy. Mm-hmm. So again, I just, I said, you know, we are putting out tons of messaging around all the different types of screening. 'cause look, there's a lot of rural Americans in this country that live over a hundred miles from the closest endoscopy suite. That's a huge barrier. I was talking to somebody today that lives in Oregon, and they have to drive 200, 300 miles to get to the closest endoscopy suite. So we do have more work to do just to get general awareness out there, both the primary care, but to mm-hmm. The general public, right. That colonoscopy Yes. Is the gold standard. But I also have to say, just as effective for people that are at average risk, are these other tests that could be easier for you and your family?

Margaret (17:51)
Well, we're, very focused on the primary care space and particularly, as a community health center, as, as one of our organizations. And was just, attending a grand rounds recently that looked at the, the comparison on the uptake of screening between a mailing campaign, mailing out the fit test or the, the colorectal cancer screening test with instructions and information versus your primary care provider or somebody on their team handing you the kit, telling you why it's important. It was like twice as effective when you got it directly in the context of your, your primary care. What are you doing in that space? How are you trying to influence, practices to really take this on and have that one-to-one communication if it's so dramatically different between that and mailing it out to people with information?

Michael (18:43)
Yeah, I've been saying the number one thing that I think had happened in this country for screenings of all sorts is covering navigation. So last year, CMS started covering some reimbursement for payments, for navigation for cancer treatment, but not necessarily for the screening side of things. Mm. And so imagine in that setting in a community health center where you, you had a navigator, but that navigator expense was reimbursable, right? Could help the center make money, or at least pay for it. You would see a dramatic uptick. So I'll give you two examples. So in the city of New York, about 20 years ago, the screening rate used to be 40% at best in all the five boroughs. And what did they do? The Department of Health said, you know what, we are gonna provide two year grants to these FQHCs, to these community health centers, to these hospitals, et cetera. And as they see their endoscopy suite revenue go up and, you know, have more patients coming in, they would revoke the grant because they would be able to more than pay for that navigator themselves. And the screening rate went up to 70 something percent. Hmm. The second thing we've been doing, we've been working with the University of California, San Francisco, and a lot of their satellite FQHCs, and we've done a similar model, but we didn't do this for colonoscopy. We did it for patients that were underserved, or at least, you know, didn't see the doctor as as much as they they would. And that got fit tests we paid for and provided language and guidance, et cetera, for number one, a navigator in their system. And then number two, what do they say? How do they do it? How do they make sure that they return that fit test? If that fit test is positive, how do we make sure they get to a colonoscopy? And we, I don't quote me on this, although I know we're live, so it's something, it was, something went somewhere like 45 to 70% in terms of follow up from a positive fit to positive colonoscopy. Mm-hmm. So, again, you guys know this, these health systems need to be reimbursed for something. And so I really truly believe in that piece around navigation.

Mark (20:54)
Well, That's great. Let me just, shift a little and ask an international question. As you look around the globe, are there population groups that have less of an incident rate of colon cancer? Or is this pretty universally true?

Michael (21:08)
It's pretty universally true. The interesting thing is this young onset phenomenon too is universally true. Hmm. There are some small pockets where we don't have enough data to potentially tell us. Like, for example, I saw that Italy, there wasn't as big of an uptake as up uptick as there was in the uk, but we think that's more about the data that we're collecting rather than actually the, the, the true sense on the ground. And I will say it has predominantly over the last, let's just say 40 years, right. Been a Western problem. Right. Meaning countries in Europe, north America, et cetera. And now we are starting to see the uptick uptick, significantly of colorectal cancer in Asia and East Asia, et cetera. You know, when we're actually seeing a lot of studies being done in China from a treatment perspective that are also starting, starting to help. And so it, it really unfortunately is across the globe, you know, a pretty significant, you know, disease.

Margaret (22:14)
Well, it, goes without saying that we're always in the midst of, federal policy and funding influencing where we are with science and healthcare, and research. Certainly, when the A CA was passed many years ago, and screening was, a mandatory benefit under insurance. We saw some positive uptakes there, in our current environment. Wondering what the alliance is seeing and how you're navigating it in terms of how you think funding for education screening the public health piece, as well as the clinical piece, will fare both, both in terms of prevention, but also in terms of research as you've described it.

Michael (22:53)
Yeah. So there's a really important case in front of the Supreme Court right now called Kennedy versus Braywood. And what that means is that the preventative United States Preventative Services task force, when it was created in 2010, as part of the affordable, as part of the Affordable Care Act, there was this tie with the Preventative Services Task force and no cost screenings for heart disease, for cancer, for diabetes, and for contraception. Well, there were some folks in Texas that didn't want the contraception to be covered, et cetera. And so what they did is they sued the Biden administration for this, what we call appointments clause. So what everybody knows, RFK Jr was appointed by the president, and he had to be confirmed by the Senate. Well, the Preventative Services Task Force is actually a volunteer group, and they are not necessarily, or they aren't confirmed by the Senate. And so this legal challenge is that this tie between the Preventative Services Task Force and the A-C-A-C-A and the no cost screening coverage is that they violated the constitu, the appointments clause of the Constitution. So they will hear oral arguments in April. We actually have an event with multiple organizations from across the country on May, I think it's May 5th, in San Diego, to really bring experts together to say, well, no matter what happens, you know, if they side on we wanna keep this connectivity or do they say it's unconstitutional, we make sure we know what is potentially could happen and will happen, because I don't think anybody, anybody believes that preventative services shouldn't happen in the United States. So we were really happy to see that the Trump administration is actually arguing the same side as the Biden administration, that this tie should still be there, because they see how absolutely important it is, to have preventative services, especially for cancer.

Mark
Oh, that's great. Tell us a little more about the Alliance. How, how is it organized? Where does it get its resources? Is it, located around the country or is it more virtual?

Michael (25:16)
Yeah, sure. So like, I, like I mentioned, my mom unfortunately died of the disease. We started a small organization in her memory in 2009, actually 2010. And then I actually led the effort to merge the organization, Christopher Life, with then the Colon Cancer Alliance, and now we're about a $35 million organization. We have, staff actually all across the country. We don't have brick and mortars across the country. Mm-hmm. Mm-hmm. We don't really truly believe in that. But we have these leave from behind campaigns. We have screening navigators, that work all the time. Get screen.org again, I'll say Get screen.org is a really good tool for patients. They can also talk to a live navigator if they have questions about screening. And then Project Cure, CRC, again, direct research funding the case by, clinical trial that we talked about, as well as a registry in a place where patients can go called Blue hq. And then we have walk to end colon cancer, which we have walks across the country. We have end colon cancer coast to coast, which is our way of, Hey, do you wanna sell, a lemonade stand or do you want it to a bake sale or what, whatever, where, where we raise millions of dollars from thousands of individuals across the country who really, truly care about ending this disease. So that's really the,

the alliance in a nutshell. We have have, you know, some galas, et cetera, and, we're really lucky. Craig Melvin from the Today Show is on our board and does a big golf tournament called Bottoms Up, in, in right near New York City every, every year. And no, I, I feel like my mom's passing was the worst thing, but it also one of the best things that could happen to me and, in my life for sure.

Mark (27:05)
And the hundred million dollars, is that a goal that you have in terms of raising money?

Michael (27:09)
Yes, we are really, we were really lucky. We have a board member who has seeded that, now with about $20 million, if not more. And we are, we're out raising money. You know, I, I didn't mention this before, but breast cancer at least did get $1.1 billion from the federal government where colorectal cancer only got about 350 million. Mm-hmm. And from a philanthropic standpoint, it's the same. They're getting way more money. And we love our friends in the, in the breast cancer world, as you saw, their life expectancy, their overall survival is higher. And reason why we're trying to do this and trying to raise the money is so that we can do the same for, you know, our fellow Americans that have colorectal cancer.

Margaret (27:53)
I know we're running, close to the end here. I wanna give you a chance, maybe a little bit of a PSA, you have a great page on your website highlighting colorectal cancer symptoms, maybe a overview. What should people be aware of, and also should they be aware of anything in terms of family history?

Michael (28:10)
Sure. Great question Margaret. Number one, screening starts at 45, get screen.org. Two is, if you have a family history of the disease, you should be getting screened at 10 years prior to your first degree relative, being diagnosed with disease Uhhuh or at 40. So I do think that that is really, really important. Again, get screened.org, and the family history piece is, is such an important, an important thing because you do want to be getting screened earlier, and a colonoscopy is only right for you, is right for you, excuse me, if you've had a family history of the disease.

Mark (28:49)
Well, that's great. And just before we end up, tell us a little more about your mom.

Michael (28:53)
Sure. Oh my gosh, my mom an incredibly human being. She was an interior designer by, by training. And, you know, she just instilled in me, obviously, to give back. And the fact you guys can imagine, just, I can't think about how proud she would be of me, but just so many others, the thousands of thousands of people that give money, that participate, that try to end this disease. It's such a, such an important, and worthwhile thing. And, you know, obviously I wish I hadn't have lost my mom, but you guys can imagine being in medicine and understanding medicine, it is really a truly a blessing to, to get you to move forward in her memory.

Margaret (29:29)
Well, Michael, thank you. Thank you for sharing that with us. Thank you for joining us and for the work you do. And thanks to our audience for being here. And just a reminder, be sure to subscribe to our videos on YouTube, find us on Facebook and x, and also share your thoughts and comments about this program. Take care, be well.

(29:51)