Speaker 1:

All right, well, hello. Good evening. Good afternoon, everybody and welcome to our webinar for February of 2023. It is Black History month and we are going to commemorate that and speak to the issue of prostate cancer in Black men, which is not only relevant for the month of February. It's a very topical issue right now, given new data that we're seeing. It now gives me great pleasure to welcome Dr. Michael Lenoir who is of the African American Wellness Project. Dr. Lenoir is a practicing allergist and pediatrician for the past 40 years. He's a board certified and a fellow of the American Academy of Pediatrics and the American Academy of Allergy, Asthma and Immunology.

He, as I said, founded the African American Wellness Project and we will talk about that. He's the founder of Black Doctors Speak podcast. He's the 114th president, wow, of the National Medical Association and former medical editor for KCBS Radio and multiple other health communications initiatives. And I couldn't think of a better guest to have with us tonight. Thank you so much for joining us, Dr. Lenoir. And you've been in practice for 40 years. You've been leading societies. You're a national or international thought leader in your field. What led you to found the African American Wellness Project? What are the goals and what's the ongoing work? And tell us a little bit about how that came to be.

Dr. Lenoir:

Well, I started the African American Wellness Project almost 20 years ago. I'm embarrassed to say out of the rage that I felt and the way Black people were treated once they entered the healthcare system. We all know about the social determinants of health, but it was the differences in evaluations and management of Black patients, not only from a structural point of view, but from the fact that they were disrespected and ignored and so the cloud of healthcare around them was often disrespectful and inferior. And I set out to establish tools that African Americans could use once they entered the system to take advantage of the opportunities that they had for the best possible medical care in many parts of the world that they were denied just because they were African American.

Speaker 1:

So you have your own story, but with prostate cancer. Maybe tell us a little bit about the journey you went through and how it reflects upon the work you're doing with the African American Wellness Project.

Dr. Lenoir:

Well, my story is maybe a bit unusual because some of the things that probably kept me from getting a worse outcome are no longer tools that are routinely utilized. I was feeling particularly well and most people don't realize that doctors are the worst hypochondriacs in the world. We go from simple symptoms to death almost in five or 10 minutes. And so I was going to my doctor for a adult checkup and I was feeling great. I'd been exercising, my weight was down. And so at the end of the visit he asked me if I wanted the digital rectal examination. I didn't really want it, but he was right there in front of me with the glove on and said, "We may as well get this done." So they did the digital rectal exam and I turned around, I could tell by the look on his face that this is not going to be the routine result that I had expected.

And he actually felt a lesion at the superior poll of my prostate. And so that then began the whole trek through the evaluation and management process. I say most doctors are no better patients, maybe worse patients than others. So I immediately went to metastatic prostate cancer, not just a digital rectal.

But then I went on through the process, got my PSA, I had a seven Gleason score on, to make a long story short, no lesions outside the prostate and was able to get by with a few CyberKnife treatments. And unfortunately for me, I have to have another assessment within the next two weeks to make certain that the treatment was successful. So my journey through the process was no different from many other people who have gone through this process and certainly many other African Americans that have gone through this process. I was immediately in the university system.

I had trouble getting an appointment, I had trouble getting people to see me on time. I even had a situation where once I was diagnosed and they weren't implanting gall seeds, the administrator came down and said that they hadn't checked my insurance so had to get up off the table, leave, make another appointment and come back. And so I took action. And I'm saying this simply because it puts a frame of reference to it. I had been the chairman of the clinical faculty at UCSF and I wrote the chairman of urology that if this happens to me, then what happens to an individual who's not as either aggressive or as knowledgeable as I am about what's supposed to happen. But eventually I got treated and it looked like up to this point the results are successful.

Speaker 1:

So you bring up a lot of important issues because number one, you had a PSA, you had a digital rectal exam as part of the screening and that's actually a little controversial. And it used to be felt to be really a critical part of the screening process. And now many primary care doctors and urologists are not even using it as part of the screen. People are jumping right to an MRI scan if the PSA is elevated and things like that. So, you can perhaps speak to this as a challenge because I know this is something that all men fear. It's a test that takes all of maybe 10, 15 seconds to perform, but it is a barrier to screening for many men.

Dr. Lenoir:

It has been certainly in the past. I happen to flow with the technology that an MRI is a far better way to make the diagnosis of prostate cancer and to identify and localize. What concerns me is too often now the biopsies are still the only process offered to many African Americans across the country. On the biopsy is what we had but the biopsies often associated with side effects, it's painful. And I think the digital rectal was a barrier for a few men, but I think it was overestimated as to how big a barrier it was as a screening tool.

Speaker 1:

I think that's well put. I mean it overestimated, it's not even necessary in all cases now. And so if that is the fear for being screened for prostate cancer, that is a fear that should go away over time. And you point out that the MRIs are probably not being utilized to their full extent in particular in the African American community. But we're hopeful that over time that will disseminate further and this will enable us to do more screening. I should point out, I said at the beginning of our webinar here that the Prostate Cancer Foundation is beginning the process of writing the first ever screening and diagnosis guidelines specifically directed to Black men and that will certainly be a part of that dialogue.

So you also, I think, identified some of the issues around getting healthcare coverage and how complicated that can be. You have the dual perspective of being an African American patient and being a doctor. And this is something that also people are challenged by, which is obtaining the financial wherewithal to get their care taken care of in the appropriate timeframe.

Dr. Lenoir:

I don't think it's unique to African Americans, but maybe certainly more concentrated in our community that the healthcare system's broken. And certainly if you've got a chronic disease or if you want screening or you want routine evaluations, it's very difficult to navigate that system. So one of the things that we do in the African American Wellness process is we fight on two fronts. First, we try to get people to understand that there are certain things you have to navigate in that system. And many times you have to have an advocate because if you don't have an advocate, you don't get the kind of attention. And then you absolutely must be prepared for your visits and speak up for yourself. On the other front of something we didn't talk about, I have been fighting with a group of physicians to continue to use race as a parameter in research.

And we published an article in New England Journal in January trying to refute this issue that race was unnecessary. We probably got in our own way because we didn't study of 300 African American families and the genetics and they were around social determinants in relationship to asthma. And it turns out it's very difficult to tell who was purely West African, were African or Indian and what percentage that composes in an individual as a self-described African American. And as you know, many universities no longer use race as a parameter in research. And I think that the research that you just described shows that I think that's a big mistake.

Speaker 1:

And I think we have, as Dr. Burnham so eloquently described, we have a lot to learn about the interface of race and biology in particular around this question because of the ancestral issues related to genetics and prostate cancer. So I would agree with you on that sentiment and thank you for taking those steps. One of the questions we struggle with at the PCF and I know you have also thought through, is the perception of prostate cancer risk in all men, but in particular among African American men and the fact that there's many men out there who are at significant risk don't know it or don't understand what that means to them. And as I think about how we want to address these challenges, we really need to come up with three components to address them. We need to have the test that we can do.

We need to have a risk adapted or an awareness of what to do with the test. But all of this begins with bringing, if it's the case of a PSA screen, bringing the arm with the vein with the blood to a place where the needle can get the tube to run the test. So it's bringing the person, the man into the place, whether it's Dr. Burnham's screening program or a standard clinical setting. And that's the biggest challenge. So what are your thoughts on how we can address that dissemination of knowledge and bringing people into access?

Dr. Lenoir:

Well, I think we need to change the perception of what getting a PSA means. I think too often is spoken about in terms of disease, not in terms of health. I mean, for you to be healthy, there are certain parameters that you have to get and that you have to know. So when we talk about prostate cancer and we talk about screening, we talk about being healthy. So that's one thing. Also, we focus a lot of our conversation on African American women because too often we forget that they're the decision makers in that family. My wife is absolutely relentless when it's time for me to get my screens and I kind of wait, I wait for the 49ers to play and the title game and then came the Super Bowl now. I got to wait for March Madness because I don't want any bad news.

But she is relentless and daily asking me have I gotten the necessary screens? But I think we need to, when I see most often now is prostate cancer. And when you talk to the African American community in terms of clinical studies and clinical trials and we talk about it in terms of disease and we talk about it in terms of metastatic disease, which we should, we talk about the social determinants of course, but

getting a PSA is part of you being healthy, not a part of disease. And so when we talk about what's available and why you should get a screen for prostate cancer or colon cancer or even vaccinated for COVID, we talk about it in terms of keeping healthy. If you want to exercise in the gym, you want to run three miles, you want to eat right and then part of being healthy is to get screened for certain problems. And prostate cancer is one of those.

Speaker 1:

And as you point, I'll just going to restate it, it's not about diagnosing a cancer. It's about if a cancer is present, catching it early so that it can be treated effectively and cured. And I showed this graph at the beginning of the hour where we saw the incidence of metastatic prostate cancer going up so quickly in the Black population and in all populations. And the implication it's felt is that this arises from the changes in the U.S. Preventative Services Task Force guidelines, which downgraded screening about a decade ago, led to decreased screening and now we are paying the price with the more men coming in with more advanced prostate cancer.

Had we seen more screening, it is possible. It is likely, in fact, that many of those men who show up now with a positive bone scan and are treated differently and not given curative treatment, many of them would've had curative amendable treatment five, four years ago because this is a chronic cancer. This is a cancer that is typically in the body for a period of time before it spreads. And so that's the idea. It's about health. It's about detecting something early that can be treated and in a more effective manner so that men can get on with their lives after prostate cancer, which is common in that localized disease setting.

Dr. Lenoir:

So yeah, I think that there's no question, but still there's this perception among Black men that the diagnosis of prostate cancer is a death sentence. I mean, I've had men, many of my friends who have been diagnosed with prostate cancer, the next thing they go to the church and ask for prayers because they feel that this is actually a death sentence. And I don't think that there's as big a perception within our communities as how treatable this problem is if detected early. And we have the same problem with colon cancer and other forms of cancer. That's why we spend as much time with Black women in this situation as we do with Black men because I think they're far more likely to get the kinds of screens that they're entitled to at the time they're entitled to get them. And they can provide the message to the family, the message to the partner as effectively or more effective than we can because they have something we don't have, which is leverage.

Speaker 1:

Well, to your point, what year were you diagnosed with prostate cancer, if I may ask?

Dr. Lenoir:

2019.

Speaker 1:

Okay. So you're now in your fourth year after diagnosis. We see many men who are living a normal life 20 years after a diagnosis of prostate cancer after therapy, sometimes even on therapy. So this idea that it's a death sentence is something that we have to get over. It can be deadly if caught late and not treated effectively, but it can be something that can be cured when caught early. And that's part of the

whole point about screening for this disease. You also bring up, you noted the Super Bowl, the 49ers and March Madness. And you bring up something that we think about a lot, which is we want to get eyes and ears of all men, but Black men in particular, on this issue of understanding that they have a risk for prostate cancer.

And sports are very important to the Prostate Cancer Foundation. We have a very successful long-standing relationship with Major League Baseball. We're doing a project with the Atlanta Hawks this month to raise awareness for this disease. And we really view sports as an opportunity for us to get to the eyes and ears of men who might want to, maybe not want to, but men who can benefit from early detection and screening for prostate cancer. So you bring up a very typical situation that we like to see.

Dr. Lenoir:

Yeah, I think that's certainly a good idea. I think what we found out during the COVID epidemic is that the most effective communicators are vetted sources in the community, doctors that they know, people that they know. And institutions sometimes expect too much of the people that they serve. I mean, for instance, if you are a big health plan and you've never been in the community, you've never talked to the people in your plan, especially plans for underserved communities and then you expect them to believe you.

And when you talk to them about getting screened and they don't know who you are, but vetted sources in the community. And fortunately big cities like Atlanta, DC have a lot of those sources, but too often the voices are relatively muted. Obviously a sports star has more bandwidth, but at the same time, I mean when people talk, the people that are most convinced about getting these various screens are people I care for and have cared for us since say we're very young. So I think we need more vetted sources in the community to stand up along with other people who rang attention to the issue itself.

Speaker 1:

Yeah, well put and we certainly don't want high profile Black men to be diagnosed with prostate cancer, but if they are, we would love to hear from them because if they want to be a vetted voice, as you say, to help disseminate the knowledge of screening and early detection and early treatment, we would be delighted to have that. Kareem Abdul-Jabbar who is just surpassed, I think it was Monday night as the leading scorer in NBA history by LeBron James. He has been a spokesperson for us and recorded public service announcements. And we find that very useful, to your point.

So I might actually ask Dr. Burnham to join back in if she is available because we're talking now about community dissemination and you're in Atlanta and Dr. Lenoir's in Oakland, California and I think you share a common goal here of disseminating knowledge and yeah, I wonder if you might want to speak to this issue of what can we do at the Prostate Cancer Foundation, but what can we do as a broader community to get eyes and ears on this topic and to not fear the test, for example and to engage on this issue?

Dr. Burnham:

Yeah, I mean I would say if to bring it up to your clinician, there's been actually a press release about a week or two ago about how there's been more diagnosis in advanced metastatic stages. And it is correlated with the lack of screening due to that recommendation. So if your clinician is not up to speed, which clinicians, especially primary care physicians have a lot of things to keep straight, it doesn't hurt for you to remind them or to let them know that you want to be tested. And if they don't think that you

should, you can let them know, you may have family history because of your race or just because it'll help you to feel better to sleep at night.

Dr. Lenoir:

Yeah, I don't think the Black medical community ever bought into that anyway. I mean, we never bought into the fact that people shouldn't be screened. Why not get another piece of information? It never made sense to us, even if it resulted in maybe sometimes overzealous treatment. So we were always out of, was certainly at the National Medical Association or-

Speaker 1:

I think that, [inaudible 00:20:33] well, the problem comes from an era in the 1990s when everybody was getting PSA screening and the treatment was not as thoughtful as it is today. Men were diagnosed with one core of Gleason six prostate cancer and would have a radical prostatectomy using the old techniques and they'd spend the rest of their life with incontinence. But now the surgery is so much better. A person who's got one biopsy core of a Gleason six cancer shouldn't be offered radical treatment and may be on a surveillance protocol or something like that.

And so I think we live in the era of risk adapted treatment. And as you say, Dr. Lenoir, it's always good to have another point of data and it's really about assuring health as opposed to diagnosing disease. So if we could, asking for advice now, we as the Prostate Cancer Foundation, have a limited amount of resources. We'd like to deploy our resources to brilliant, young scientists like Dr. Burnham who we're going to spend hopefully 40 years researching this problem. No pressure. But as we think about putting resources towards solving one of the problems that we're seeing, which is this increased risk of metastatic prostate cancer in Black men, what did the two of you think we should be doing?

Dr. Lenoir:

Well, I think you have to talk to people where they are. I think I've always been a big believer in mass communication. I think you can sit at a place during the pandemic. People had lots of time at home and things that they could do and they could sit and listen to lots of different kinds of information. I think now we're back to people not having so much time. So we have to get them where they are. And we are going back, we've done a lot of social medias, I'm sure everybody has. But we're using more traditional media again and then you can get at least a message more than 10 or 15 seconds where people are forced to listen, in between music or whatever. So I think we need to continue to use social media, but I think we feel that the traditional media, us being ignored and we need to change that.

Speaker 1:

Yeah, and we agree with that. It's finding the right resources, finding the right outlets and doing things like this webinar tonight, which will be on pcf.org for a long period of time and accessible to those who aren't able to join us live. Dr. Burnham, your thoughts on spreading the word even further and other things that you should do? And your chance to give advice to me.

Dr. Burnham:

Yeah, I think exactly what you all are doing. When I saw the press release maybe a month or two ago that you guys were assembling this panel, I just sort of sat back and said, "Who's going to be on this panel?" And what I really appreciate is you all are choosing people who are not new to this, they're true to this. There are people who they have long before the media comes out, well two weeks ago, saying,

"Oh man, prostate cancer's on the rise. Oh, this may affect Black men differently." These are scientists and these are clinicians who've known this as a problem for a long time and have made it their life's work. And that's who you're tapping into. And they are the ones who've had their ears to the street. They're the ones who are in the clinic. And so I'm privy to who some of these people are and I think you've just got the right team together to address this very comprehensively.

Speaker 1:

We're proud to be doing that and we'll look forward to future conversations as those guidelines roll out. And let's hope in the long run we're able to reverse those curves that we saw at the beginning of this. I can't thank the two of you enough for joining us for the work that you do on behalf of science and of Black men and all men with prostate cancer and those who love them. And I look forward to future conversations. And Dr. Burnham, 40 years, I guess. So get to work and keep doing what you're doing. Thank you so much for all the work you're doing and on both fronts, the both social determinants and the biological determinants.

Dr. Lenoir:

And I would like to give a shout out to the African American Wellness Project. We have some very robust content on our site for the targets, African American men with prostate cancer that we developed with the Linkwell Foundation.

Speaker 1:

Thank you both so much for joining us and everybody listening, thank you for joining us and have a great rest of your day.