

Prostate Cancer Uncensored Podcast - with Guest: Stacey Loeb



Jamie Bearse: Hello, and welcome to Prostate Cancer Uncensored, a podcast produced by ZERO – The End of Prostate Cancer.

I'm Jamie Bearse, CEO at ZERO. This podcast is about fake news, or rather fake news for prostate cancer. Unfortunately, misinformation about this disease is everywhere; it's on social media, websites, digital ads, brochures, you name it.

And someone who knows a thing or two about fake news when it comes to prostate cancer is Dr. Stacy Loeb. Dr. Loeb is a urologist at NYU Langone Health Center in Manhattan, New York. She also hosts the Men's Health Show on SiriusXM US-Canada satellite radio. Dr. Loeb, we're grateful and honored to have you with us today on Prostate Cancer Uncensored. Welcome

Stacy Loeb, MD: Thank you so much for having me.

Bearse: We're honored to have you. How are you?

Loeb: Great, great. Good to be here, and what a really important topic.

Bearse: Definitely. And now, Dr. Loeb, when we were talking the other day you had mentioned that it's actually your grandfather that got you into the prostate cancer cause and working in the urology field. Is that right?

Loeb: That is absolutely right. My grandfather and I were very close, he raised me, and he passed away from prostate cancer while I was in medical school. So at that point in time, I decided to dedicate my career towards helping other men and their families who are going through this.

Bearse: That's terrific that you're helping other families. We have a connection there that my grandfather also passed away from prostate cancer after fighting it for more than a decade. So we have that connection there too. What's your favorite memory of your grandfather?

Loeb: Oh, gosh, I mean there's so many. But I remember he would always come to my tennis matches after school, and I would sleep over at my grandparents' house. They were just really wonderful people, and I'll just miss them always.

Bearse: My favorite memory of my grandfather: I would sit on his lap and he would always have a Peppermint Patty for me. So I think that's where I got my chocolate addiction from.

Loeb: Very nice.

Bearse: [laughter] Now aside from being a urologist and a radio host, Dr. Loeb, you're also a researcher. And the research that I'm interested in hearing most about is prostate cancer and the vast amount of misinformation about it online. Can you tell us about your findings or some of the most recent research that you've worked on around that?

Loeb: Yes, absolutely. So, you know, the internet I think is really a double-edged sword for patients because there's certainly a lot of great information out there, including on social media. It's a great way to keep up on new research findings and connect with doctors and researchers in the field. However, the content really is not vetted, and there's also a lot of false information circulating out there.

We started addressing this topic by looking at the first 150 YouTube videos on prostate cancer. What we found is that a significant number of these videos contained biased or misinformative content either within the video itself or in the comments section underneath.

Bearse: And now through the research, Dr. Loeb, what has been the biggest prostate cancer myth that you've seen be repeated over and over and over again?

Loeb: Well, you know, quite a few things. Some of the information is just outdated. So, for example, prostate cancer screening guidelines have changed. At one time the United States Preventive Services Task Force recommended against prostate cancer screening. This was later revised to recommend shared decision-making about the pros and cons of screening. But there's a lot of videos out there that just say that the US Preventive Services Task Force recommends against screening. So one issue with online information is that once something is posted online it just basically remains up there in perpetuity unless it's actively removed. So you have to be very careful as a health consumer about looking at the date of the information and whether it's a very recent piece of information, because things are just constantly changing in medicine.

But then there were other videos that just simply had wrong information. One that comes to mind is a video about injection of herbs into the prostate as a treatment for prostate cancer, which is not evidence-based. This is not a standard treatment that's recommended in the guidelines, however this video has more than 300,000 views on YouTube. So I find this very concerning since we have no research indicating that this type of treatment would work, and, in fact, injecting herbs into the prostate could even be potentially very dangerous.

Bearse: I bet. You had mentioned the USPSTF around prostate cancer screening. One of my concerns with the information that remains out there over de-recommendation from the USPSTF, which basically in layman's terms means don't bother, or you don't have to talk to your doctor about prostate cancer screening. One of my concerns is that it's still that old practice, or that old recommendation is something that really continues to stick in the minds of general practitioners when men who are at risk for prostate cancer come in and talk about some of their health concerns that they may or may not should be thinking about. Do you see that as a concern too?

Loeb: Absolutely, I think it's a huge problem. And, you know, the large amount of online content that continues to discuss those old recommendations would only serve to perpetuate this. So I think this is a

really big problem that as the field changes and the science changes there's a lot of old stuff that stays on the internet and kind of remains in the culture of medicine that is really no longer applicable.

Bearse: Definitely. And this question may be obvious, but you had mentioned that there's not only dated information out there, but just plain and simple wrong information – and we'll get into more of that – and I know you gave me an example around herbal injections into the prostate. So there's a lot of wrong information out there. Why do you think this is so harmful to men?

Loeb: Well, I think that first of all if patients and their families see misleading information online it could change their decisions about their care, their perceptions about treatment options. And even if patients and their families end up discussing these options with a doctor and still receive the standard treatment, if a large portion of the medical visit is spent discussing things that people saw on the internet that are not evidence-based, then that's that much less time available to discuss the standard treatment options. So my concern is, 'can it affect decision-making among patients and their families if they see some of these videos with false information that's really compelling?'

In the case of the video about the herbal injections, that's a very popular video. So just because something has a lot of views or likes on social media doesn't mean that it's good or that it's accurate. But this is a trap that we can fall into. I myself am subject to this. When I'm trying to purchase something on Amazon, I do take into consideration the number of positive reviews that something has received. But the truth is these could be from bots, these could be from people working for the company that sells the product, there's no way for me to even vet the people who are reviewing the products that I'm looking at on Amazon, and the same kind of thing would apply to these pieces of content about prostate cancer.

So I think your safest bet is to go to sources that you know are trustworthy for content about prostate cancer, such as [ZERO](#) or some of the national health organizations, governmental groups where there isn't commercial bias and you know that the information is trustworthy.

Bearse: Well, great. And you were talking a few minutes ago about herbal injections into the prostate. You had mentioned that had thousands upon thousands of views on YouTube, being a really well produced video. It's almost understandable that men might think that that's legitimate, right, and it almost goes to your Amazon example.

Loeb: Yeah, absolutely. There were some videos by very prominent academic clinicians and researchers in the field that had very few views, but these videos were not produced with high production quality. I think it's very difficult as a clinician and a researcher. I don't have a videography team at my disposal. It would take a lot for me to make a very well-produced video, whereas commercial entities have a large budget for these types of materials.

So if you think about it, many of the videos that don't really have a high production quality could be coming from some of the people who are real experts in the field. So just because it's a snappy video with good production quality doesn't mean that the information is accurate. And vice-versa; if a prominent physician is sitting at their desk and filming something on their iPhone, it may not look very snappy, but they may be sharing really important information.

Bearse: Definitely. And the web is really the first place that many men go – really anybody goes to – when they hear about if they've got a health problem. So men when they hear the words "prostate cancer" or

“you’ve got prostate cancer” uttered by their doctor, one of the first places they go is the web. So with all that fake news, not only is it just harmful to them, but it can really be a waste of your time, too, right?

Loeb: Yeah, definitely. I think it’s a big waste of time.

Bearse: Well, for yours, too. You had mentioned that you’re putting together a bigger and bigger team all the time to go through some of these videos and misinformation, that I’m sure that you personally get caught into doing it a lot, too, no?

Loeb: Right, absolutely. I think it’s a common occurrence that patients come to the office and they’ve seen something online and they want to talk about it, and really it has no relevance to their case. And it concerns me that we’re spending precious minutes in the short encounter dispelling myths.

But we are working on this, as you mentioned, in the research setting. We have developed a larger team of physicians and researchers who want to address this issue, so we’re looking into new possibilities. For example, could there be a computer science approach to this where we use machine learning to help us identify potentially misinformative content about prostate cancer?

We have been working on this. We just published a preliminary conference paper about this for a multimodal modeling conference, and basically with our preliminary algorithm, we have about 74% accuracy of the model to identify misinformative videos about prostate cancer. So we’re excited about this and we’ll see where this research goes.

Bearse: And you had mentioned when we were talking the other day that there’s a lot of work ahead of you. Give me a ballpark figure, out of 10 pieces of prostate cancer information that you would find online, what’s the percentage of it that’s misinformation or just not true?

Loeb: Well, in the sample that we looked at on YouTube, 77% of the top 150 videos had something that was potentially biased or misinformative within the video or the comments, so it depends if you watch the whole video, if you read the comments underneath. But we did see some surprising things. Believe it or not, patients and their families are asking each other for medical advice in the comments section on YouTube and giving and receiving advice; so there were people asking what treatment should my dad have for his prostate cancer, and another user writes back. So bottom line: I think it’s very important to let the buyer beware, and for health consumers to be very discerning about where they’re going for their information.

Bearse: That’s astounding, almost 4 out of 5 pieces of information about prostate cancer on the web may be biased or have some sort of misinformation in them that prostate cancer patients and their caregivers should be aware of. That’s astounding. But let’s give our listeners some advice, Dr. Loeb. We can’t stop men from going online, so when they do, how can they make sure that the info that they’re getting is good or reliable?

Loeb: Well, I have a few pointers. Number one as I mentioned, the date of the information is very important. There are new drugs that are approved, guidelines change, new research studies come out that change the sequence of prostate cancer treatments. So this is a constantly dynamic field which is great news, but the downside is that information can quickly become dated. So looking at the date of any content that you’re reviewing is very important.

Another piece of advice I would say is to ask your doctor where to look for information. I think that we can all agree, both patients and physicians, that a clinical encounter is too short and it’s natural that patients and

their families are going to need more in-depth information. And that can be a prospective discussion between patients and their physician – what websites do you recommend, do you have any videos, any books, other resources? So rather than trying to track things down on your own, getting some suggested resources directly from your physician or from a trusted organization like ZERO.

Another piece of advice is just to talk about things that you see online with your doctor. If something is pressing on your mind that you reviewed, or if there's something that's so compelling that it makes you want to change what you do, or even not do the treatment that was originally discussed with the doctor, I think it's really important to just be upfront with that. There's been a lot of research about the impact of the internet on patient-physician communication and it's a really mixed bag, but it can be a real supplement to patient-physician communication.

A patient who is really well informed and has read a lot about their options, really presents new opportunities for the patient-physician discussion. So just making sure to let the doctor in on any doubts or concerns that you may have, or that have been raised as a result of what you read online, so that they can be talked through.

Bearse: And, Dr. Loeb, I believe you split your time between doing research and also on the clinical side seeing patients. Is that right?

Loeb: Yes, that's right. I have three clinical days and two research days. I really enjoy having both components as part of my job, because I see it as the circle of life. Some of my best research ideas have been inspired by questions that patients ask me in clinic; for example, my first NIH grant looked at comparing different strategies for active surveillance of prostate cancer, what happens over a lifetime if you were to have a biopsy every year versus every 5 years, or perhaps do an MRI instead of biopsy.

And there really aren't any randomized trials comparing these different approaches, but patients were asking me, "do I really have to have another biopsy this year." We didn't know the answer, so I made a grant proposal to create a mathematical model that would compare the outcomes of these different protocols over a lifetime horizon, and it felt very validating to then go back to the clinic and tell these patients the results of the research, what we found, and what I would then say about their case.

So I see the clinical and research side as really being an ideal marriage, and there's nothing better than using patients' questions to inspire what really are the most important topics to look at and research, and then to go back to patients with the results.

Bearse: Yeah, it must be amazingly empowering to, like you just said, hear some of the questions that you're getting from your patients on the clinical side, and then to go back and over time, be able to find the answers that they're searching for and be able to deliver on that.

Loeb: Yes.

Bearse: That's wonderful. And putting on my patient advocacy hat, and we're talking about misinformation around prostate cancer and where to go to really get the most accurate information, are there websites that come to mind, you know, maybe two or three websites that come to mind that you trust almost implicitly that you send your patients to?

Loeb: Yeah. Well, I mean, I think right here we're talking about it; you can go to zerocancer.org, I think that's definitely a great website. I just finished my term as chair of the Technology and Publications Committee for

the Urology Care Foundation, and there's a lot of good resources available on their website. They also have a print magazine and sometimes sponsor some tweet chats about prostate cancer.

I've also been working with the Prostate Cancer Foundation on some digital content for patients; I helped with the patient guide that they've come out with that discusses different treatment options, and I also work with them to host a once-per-month prostate cancer journal club on Twitter. So anyone who's interested can certainly participate in that, it's open to anyone and it's indexed on Twitter using #prostatejc, which stands for Prostate Journal Club. So we discuss one new article per month there, and a lot of different clinicians and scientists in the field participate in that. So those are a few sources that come to mind.

Bearse: Yeah, it's interesting you bring up the Prostate Journal Club and having that Twitter discussion happen every month. I remember going through and studying for my MPA and hearing one of the professors talk about if you're working on a research project, one of the most helpful tools out there is actually Twitter to communicate among your fellow researchers to get discussion going around some of the projects that are being worked on. So would you say that's a plus. There are places on social media like Twitter or Facebook or whatever that can help spread misinformation, but then you also have it on the flipside, that it's been able to, would you say, it's been able to speed connection among researchers or help collaboration in that way?

Loeb: No question. I think there definitely is a very positive side to social media. ZERO is very involved in social media, and I think it is an important way for patients to get information and support as they go through the process. Some of these things that I mentioned, like the Prostate Cancer Journal Club on Twitter, I think it's really a neat concept.

We have a journal club once a month for NYU Urology. My department meets in one room in the hospital and we discuss six new journal articles that came out, but that is only within our hospital. So the traditional journal club concept, although it's nice to keep up to date on research, it's a bit insular, that it's geographically limited and it's not open to the public.

So these Twitter-based journal clubs is a nice way for discussions about new research to happen among a multidisciplinary group of doctors and scientists from all around the world, and which is open to the public, and therefore patients, caregivers, and other stakeholders can also participate in these discussions.

So I think in a way social media is a great equalizer, it levels the playing field where everyone can view the same information at the same time, form connections. I myself have become connected with many other professionals working on prostate cancer from around the world through Twitter and with many patient advocates who actively participate in these discussions, so I think it's really been fantastic.

So I wouldn't want to give an overly negative viewpoint of social media, I guess you could say there's a lot of promise and a lot of peril, which is why it's just important to be very selective about where you're looking for information.

Bearse: Now, as a member of the public or the general public, what would you say that we could be doing better as a society to spread the correct information around prostate cancer or health issues; what are we not doing that we should be doing?

Loeb: Well, I think ZERO is already leading the charge. I think if there are websites where there's a catalog of resources, where people can look for information, that that's a good start. Certainly if you see anything

that's misleading or false, reporting that content would be a good start so that hopefully we can start to get some of these things taken off the internet. And creation of more content that is good, let's try to drown out the misinformation.

They say the solution to pollution is dilution, so as a healthcare professional, I think that part of our mission is to get involved in the public discourse. That's why I participate in social media actively and why I host the radio show on SiriusXM. I see it as part of my duty to help raise the signal above the noise and provide good quality information to the general public. So I would encourage other healthcare professionals and scientists to actively participate in these public networks and help set the record straight.

Bearse: And I was just going to say that, that's definitely some place that men who are diagnosed with prostate cancer or their caregivers or families should go. You have quite a following on social media on Twitter, I believe your Twitter handle is [@loebstacy](#) – it's loebstacy – and Dr. Loeb has almost 13,000 followers on Twitter. I know that doesn't necessarily validate that what she's saying is true, but everything that you are saying is factual and true, and you're dedicating your career toward breaking down that misinformation and putting out there the correct information so men can make the best-informed decisions around their prostate health. So that's definitely some place to go is to follow Stacy on Twitter, and certainly listen to your show on SiriusXM. What channel is that on?

Loeb: So the show on SiriusXM channel 110, it's the [Men's Health Show](#). It's live on Wednesdays from 6 to 8 p.m. EST, and there are repeats throughout the week. If you miss the show, it's also available for subscribers in the on-demand section of the SiriusXM website. One bonus of listening to the show live is that we do take questions from callers, so if you are a patient or a family member and have a question about prostate cancer, we get a lot of great experts on the show. I interview all kinds of different people about different prostate cancer topics, and you're always welcome to call in and ask us a question.

Bearse: Now, what's a topic that you keep going back to over and over again, Dr. Loeb?

Loeb: Well, you know, really all different aspects of prostate cancer. Our next show is on prostate cancer genetics, and about BRCA in men. Certainly a lot of people have heard of BRCA in relation to breast cancer and Angelina Jolie, but there seems to be a lot less awareness among the public about the relationship between BRCA and an increased risk of prostate cancer. So that is the topic of this week's show.

We're also going to be doing a lot more on diet and nutrition in prostate cancer on upcoming shows, and about prostate cancer treatment. On my last show we discussed some of the newer approaches to radiation therapy for prostate cancer and some of these shorter-course radiation therapy options. And as new research comes out, we try to just invite the people who write the studies to hopefully give the public the first glance at research that comes out.

Bearse: It sounds like we're aligned on much of this. I just recently did a [ZERO Live on Facebook with a doctor talking about BRCA mutations](#) around prostate cancer and how important it is to continue to get somatic and germline testing around BRCA2 genes to see how your body changes over time and how that dictates your risk of having aggressive disease. Definitely an important topic.

Loeb: Yeah, for sure. Really a hot area now is prostate cancer genetics, a huge topic of research, and I think this is going to be extremely important moving forward. Already there's some targeted therapy options for prostate cancer for patients who have specific genetic mutations, and I think we're just at the tip of the

iceberg. This is just going to keep advancing over the next few years. So as I see it, a decade from now, probably everything will be genetically determined.

I suspect that all men will undergo germline testing at a young age -- this will help determine their risk of developing prostate cancer in their lifetime. Hopefully there will even be targeted prevention approaches where depending on your genetic makeup, certain prevention strategies might work for you better than it would for other people. And then treatment. Probably treatment of the future is going to be based on genetic pathways and targeting the specific mutations in each case. So we're not totally there yet; we're only at the beginning, but I think it's really an exciting time of moving forward into precision medicine, and I encourage all of the listeners to stay tuned on that topic.

Bearse: Definitely, I couldn't have said it better myself, that that's going to help get us to generation ZERO, the first generation of men free from prostate cancer, to be able not only to detect the disease early, but be able to determine what's aggressive disease and what's a benign tumor that you can live with.

Dr. Loeb, thank you for sharing your story with us, and helping us navigate the sea of misinformation out there about prostate cancer. As you said, for our listeners, a place you can always trust for information is zerocancer.org. But then also following Dr. Loeb on Twitter, it's @loebstacy – again that's on Twitter – or tune into her show on SiriusXM channel 110, the Men's Health Show. You can always trust those two places for getting accurate information around prostate cancer.

Dr. Loeb, thank you for joining us today.

Loeb: Thank you so much for having me.

Bearse: And once again, I'm your host, Jamie Bearse. And thank you to each and every one of our listeners for tuning in to Prostate Cancer Uncensored.