Prostate Cancer Uncensored Podcast - Part One
With Guests: Jay Jay French and Dr. Nilay Gandhi

Jay Jay French: It's a well-worn cliché. If I can help one person, it'll be better than having nobody relate to this thing so thank you for giving me the platform.

Jamie Bearse: If you know the songs “We're Not Gonna Take It” and “I Wanna Rock” then you're going to know my guest on today's podcast. His name is Jay Jay French, and he's the guitarist for the heavy metal band Twisted Sister.

Bearse: Hello everyone, I'm Jamie Bearse, CEO at ZERO and host of the ZERO Podcast Prostate Cancer Uncensored. Jay Jay French is not only a rock star, but he's a prostate cancer survivor, and I was fortunate enough to spend time with him recently to talk about everything dealing with prostate cancer and the public eye to his next twisted business adventure. Also in this podcast, I chatted with Doctor Nilay Gandhi. Dr Gandhi will set the record straight about possible factors that cause elevated PSA levels. For example, can sex or riding on a bike affect your PSA? Dr Gandhi will have those answers a little bit later.

You're listening to Prostate Cancer Uncensored, a podcast produced by ZERO - The End of Prostate Cancer. This episode is brought to you in partnership with Bayer. Now, here is part one of untwisted straight talk with Twisted Sisters Jay Jay French. Jay Jay spoke to ZERO from his home in Manhattan.

Bearse: People obviously know you from Twisted Sister and you've remained in the spotlight since the 70s and 80s. When you were diagnosed with prostate cancer, was your first instinct to keep it quiet or to speak out about it in more of a public way? Tell me about that.

French: Prostate cancer was not my first medical challenge. I had a really bad case of atrial fibrillation and needed an operation. I was one of the first people in New York to have abolition done, and it was a disaster. When they pulled the catheters out, they tore my heart muscle, flooded my chest with 400 cc's of blood; my lungs collapsed and they wound up in the ICU. Not only did they not cure my AFib, but I got sicker. This is a backdrop to the fact that prostate cancer was always floating around because my father died of it. My brother and I talked about it all the time, but I had to deal with this AFib business. I had to become a specialist in AFib, and

then my daughter was diagnosed with Uveitis. In case you don't know what that is, it's like arthritis of the eyes. It's a complicated and rare eye disease that causes blindness. I had to become educated in Uveitis, so I became so educated in AFib that I could talk to any doctor about it.

I became so educated about Uveitis that I have a whole website where I explain it. The guys who treat it thanked me for explaining it because it's a hard disease to explain. I've raised money for the Uveitis Foundation. I don't need to raise money for the Cleveland Clinic. They got enough places and they're the ones that cured my AFib. They have a lot of resources, but there's very few resources for Uveitis so I realized how powerful it was. I was able to bring awareness to Uveitis and bring money to that particular orphan's disease as it's called because it's part of the rheumatoid arthritis family, but it's a very small offshoot of it. I think there's maybe 30,000 people in America, as you can imagine that's not a lot. Most people don't know about it.

When I finally had prostate cancer, my instinct was to not talk about it. My instinct when I had the heart operation was not to talk about it, then when I got comfortable with it after a while I started talking about it. And then, I started talking about Uveitis and my daughter. She said ‘I’m comfortable with you talking about it,’ so I think it was a natural evolution of becoming comfortable with it. Basically saying what the hell, what's the point of not talking about it? To preserve some sense of some image or something?

It's crazy. I think it's so interesting that you asked me about that. My initial instinct was I don't want anybody to know. After a while, it was like everybody should know because everybody should be aware of the signs. The awareness matters. It became important to me to be an advocate of it. It just took a little time to get comfortable with it.

Bearse: From my perspective in working in the cause for so long, us guys don't want to talk about our health. In fact when it comes time to go to the doctor's office, usually there's a woman who cares about us behind us with a 2x4, making sure that we go see the doctor. When it comes to talking about our health, particularly issues below the waist, we don't want to talk about these things.

French: I contacted all the guys I knew with prostate cancer to get their stories. I called them up and said tell me exactly what happened, exactly how you're dealing with it and exactly what the long-term results are. I have a web of like five or six people, including my brother being one of them, who I would regularly talk to see how they were doing. From there, it was just a natural progression.

Bearse: And you tapped into each one of them to get their story to help you decide what pathway to take?

French: No, I knew my pathway. They were just these guys who had it and had their procedures. Maybe I said ‘why did you choose the procedure you did,’ because there's a variety of ways to handle it. There's radiation in seeds or there's operation or there's radical

prostatectomy or combination of many of these things, which if you have prostate cancer, you'll learn about. I wanted to know why they chose what they chose and how the results were, but then I did a lot of reading and of course I had been given biopsies for 12 years.

I was diagnosed after five biopsies, and biopsies are not the most fun things in the world. If you don't like going to a dentist, you're definitely not going to like having a biopsy. The first time I was told to have a biopsy; I had it and it was very uncomfortable. My PSA was like 4.3 which is right over the line, and then my next blood test showed, a year later, like a 4.9 or a 5.1. After the second one, I started to do research. Why does your PSA go up? That's a natural question. Is it going up because you've got prostate cancer? Is it going up because you have an inflammation? Is it going up for any one of a number of reasons?

I found some things that blew me away. The next time I had a blood test I was at 5.7. I found out that if you have an ejaculation experience within 48 hours of your blood test, your PSA could be up to 20 percent off. I also found out that if the blood is not refrigerated immediately, it can be off by another 20 percent. That's a 40 differential. Before I had my third biopsy, I said to the guy 'let's wait one week.' I abstain from sex and then I went to a laboratory where they chilled the blood right away. My PSA went from 5.7 to 4.9.

That was a wake-up call. I just saved myself another biopsy. They don't tell that to people, so I say to doctors: 'why don't you tell that to your patients?' I don't know. You don't tell your patients that there can be a 20 swing if you have any ejaculation. I mean forget having sex with another partner. You cannot have an ejaculation. I found that astonishing that they kept that some sort of a secret like what the hell is that about. I found it astonishing that they don't tell you that if your blood isn't chilled it could reflect a 20 percent differential which means that decisions can be made based on this stuff that shouldn't be made. I thought that was terrible. At that point, I switched urologists.

Bearse: Even riding a bike for a prolonged period of time increases your PSA.

French: There's a whole bunch of things. If they don't tell you these things, it's a shot in the dark. My brother was diagnosed at the age of 66. My father died of it at 73. He had cancer in his bones; his bones disintegrated, but the basis of his disease was prostate cancer. I asked my doctor; I said 'how long does it take to get into the bones' and he said 'untreated five years, six years depending.' I said 'it's a good bet about 66; he probably got it and never went to the doctor. He said 'probably.' My brother at 66 got it, so I was 56 when my brother was 66. Over the next 10 years, the numbers kept going and going and going and going. The biopsies were negative, and then finally I hit 66 as bingo.

At that point, I had picked my urologist. I had studied every version of possible treatment. Although prostate ablation hadn't been pioneered yet, CyberKnife had been pioneered, so I had all these options I looked at. I chose the option that I wanted to have. When you talk to people about this, what's interesting is that the guys who've had radical prostatectomy all say exactly the same thing. When I say why did you have that, they go because I just wanted it out of my

body. They didn't want to deal with radiation. They didn't want to do the mushy prostate which stays in you. Let me be clear, if you keep it in you but there has been radiation, your desire and your necessity to pee doesn't decrease because the prostate has expanded and pushes on on your aretha. Who talks about these things? What guys actually say what I'm saying? Not that many of them. I said you gotta have straight talk, and I became a straight talker.

Bearse: That's great. Tell me about it, you mentioned your brother and your dad had prostate cancer too. When you got diagnosed, what went through your mind? I'm going to speak out and be a straight talker about it, but take us back to that moment.

French: It was a discussion I didn't want to hear but was inevitable in my mind. My PSA got up to 9.9 and then it went back down to 8. At 9.1, they had done extensive MRIs and they said 'unless we see an MRI change, we're not going to do another biopsy on you.' I had four at that point. About 18 months goes by and now I'm 11.1, they did an MRI and they saw shadows. My doctor said 'you know what we've just pioneered, a new biopsy; it's even more invasive than the old biopsy; it's a double biopsy from front and back.' I said to them 'in the past I've always been locally anesthetized but awake. They said 'you can't be awake for this we gotta knock you out.' I said 'that's fine by me.'

They knocked me out and they found it. They called me in and said 'not only do you have prostate cancer but you have a gleason of 9.' I go from nothing to gleason of 9. How the hell did that happen? Someone who watches it as much as me. I said 'I can have it removed' and they said 'you can, we do that here, but we also do radiation so why don't you meet with an oncologist.' It's a fair thing to do, talk to an oncologist, ask them if it's something they can cure as well and I did. At that point, CyberKnife had been around, but CyberKnife only works if your gleason is under 6 from what I understand at least. I was past the number that CyberKnife was even an option with five treatments. For those of you who see those posters all over the place, CyberKnife, CyberKnife, CyberKnife, you have to have a lower gleason score. Are you aware of that by the way?

Bearse: Yeah.

French: Okay again, you got to educate people about this so he talked to me about the radiation. My brother had radiation in seeds by the way. I said to my urologist: what would you do if this was your kid or you? He said 'I would have it removed but that's my choice because I'm a surgeon that's why we have other people here.' This was at NYU Langone. I thought about it and said 'I want it removed' so I had it removed. That was why that decision was made. It was not my brother's decision. I mean my brother decided to have seeds in radiation.

Bearse: Now that your rising PSA and knowing that your dad and your brother had it, factor in that.

French: Meaning...

Bearse: Well meaning, did (that factor in on) your decision on what you wanted to do for a treatment?

French: No, no, no, no I always knew I wanted it surgically removed, actually in the back of my mind. More of my friends have had surgical removal than have had seeds in radiation. Also, I didn't like the option again. Sorry if you're hearing sirens in the background folks, but this is just the way it is when you live in Manhattan. It was made clear to me that if you have it surgically removed and it comes back, you can always have radiation. If you have radiation first, you can't have it removed because the shape of the prostate becomes very gummy and it becomes impossible to remove it. You have a back door solution when you have it removed so I chose the back door solution which is if it comes back, radiation. After they did the biopsy, they found that I did not have a gleason 9. I had a gleason 7 which was better to hear, but I'm assuming the way women look at breast cancer is they can tell you that they got it all, but until you die, you can always get it. Prostate cancer is a tricky little disease. All it takes is one cell to float around the body, one cell to get out and float around and find a home that may or may not kill you at some point. You got to be aware of it and then you live with it for the rest of your life.

Bearse: Go through your mind before they even told you had prostate cancer. Like yeah, I think I might have it because I have a rising PSA, my brother had it, my dad had it or you just kind of put it out of your mind.

French: I don't know, I think until you're diagnosed with it, you don't have it yet. The thing about biopsies for people who don't understand, there's no easy answer. They can do a biopsy. They can take 12 cores out and miss it completely. Think about this: they take cores in a biopsy, cores of material are taken out of your prostate and examined under a microscope. Now, your prostate has a certain size and these cores are small. If you think about this, I had four biopsies where 12 cores were taken out each time. I had a fifth biopsy where 24 cores were taken out. My joke was: do I have any prostate left? If you take out that many cores and there are times they take cores out and miss it completely, well you still have prostate cancer except that the cores they remove are not hitting the spot which is why MRIs are important because it allows them to target the removal of the core in an area that's suspicious.

Up until that point, had I had, it was not detectable because they didn't hit it. When they did the front and back one, targeted. Bingo, they hit it. There were words I didn't want to hear, but I always said to my wife ‘one day I'm going to hear them, I know one day they're going to tell me ‘this is it’’ and they did. I said ‘let's schedule the operation as soon as possible, let's just get on with it.’ I made a joke. I said ‘man I love sex, I don't want to lose my sex drive, what happens if i just decide I don't want to have the operation and I just want to have sex until I die? The doctor said ‘well, you'll have a good couple of years until the pain becomes excruciatingly bad and your illness at the end is going to be horrible, but you'll have a couple more years if that's the choice.’

Trying to maintain a sense of humor about this thing like you're trying to be funny about it or try to be flip about it, I said ‘what if I decided I want to just screw (it), I'm enjoying my life and I don't want to destroy my sex life, it’s great.’ They go ‘well it's going to be great for a while, when it hits

your bones, man it's not going to be nice." That funny joke conversation lasted about two minutes and it was let's get back to the issue at hand.

Bearse: Gotcha. With your prostate cancer, did it spread or was it contained in your prostate?

French: They said 'it had looked like it had broken out of the capsule, but they took everything out around it including the lymph nodes and found nothing.' He said to me 'just keep getting checked every six months as long as it remains in those numbers that are considered undetectable, you're fine. If it starts moving, then we have to watch it. If it moves in a way that reflects some sort of a pattern, we'll have to deal with it.' In the last three months, three friends of mine who have had prostate cancer, one of which was radical and two of which were radiation, had it come back after 10 years, 14 years and 15 years. Well, that's a sobering number.

You've been listening to Prostate Cancer Uncensored and our guest is Twisted Sisters Jay Jay French who himself is a prostate cancer survivor. We spent quite a bit of time with Jay Jay and in part two, he talks about the twisted side effects of prostate cancer. Be sure to download and listen to that episode as well.

Bearse: A lot of great medical topics came up in our conversation with Jay Jay, so I want to expand on a few of those. I'm joined now by Doctor Nilay Gandhi. Doctor Gandhi is a surgeon and a urologist with Potomac Urology in the Washington D.C. area. He's also a member of ZERO's medical advisory board. Doctor Gandhi, we mentioned earlier in this podcast that there are these factors that could cause an elevated PSA like riding a bike, sex and Jay Jay even mentioned the refrigeration of blood. Could you tell us more about these other factors as they relate to an elevated PSA?

Gandhi: When we talk to our patients, we do let them know that there are certain factors that can increase your PSA. Most commonly, we do see that in times of a urinary tract infection or prostatitis or something that can cause some sort of inflammation to the prostate which causes them to release cells and release PSA. Typically in those times, I would not want to check a PSA level because it would be higher than we would normally expect so in times of a urinary tract infection or prostatitis usually we would hold off on it. We do see a natural increase in PSA as well just as men get older and their prostate gets bigger. With BPH and enlarged prostate, we can see some elevation. In terms of with sex, it's related to ejaculation because the prostate involved in this process again. It can lead to transient increases in your PSA levels as can bike riding.

There's been some studies looking at this to say: what is the effect on your PSA after bike riding or after sexual activity and ejaculation? I think it's rather commonplace now that discussing this with patients that we typically would want to wait anywhere between 24 to 72 hours after those activities to wait before you draw a PSA level. Something to also keep in mind is that there's a common medication which actually can decrease your PSA. This is Finasteride, and this is used rather commonly in men (for) either propecia for hair loss or Proscar. The difference between

those two is the dosing of Finasteride but that's used for an enlarged prostate. Keeping that in mind that there are factors that can increase your PSA, but there are also very common medications and other factors that could also decrease your PSA that have to be taken into account.

There was a study in the late 90s looking at how storage of PSA or even other blood samples can impact values. What they initially had found was that it can impact free PSA more than anything but did not really have an effect on your total PSA. A lot of these blood tests, whether it's using the total PSA, a free PSA or there's some newer blood markers and biomarkers that are available, are using them all in combination together to truly assess a patient's risk status.

Bearse: Jay Jay referenced a mushy prostate being something that men can experience if they opt for radiation versus a prostatectomy. How does radiation affect the prostate?

Gandhi: Radiation typically is using x-ray beams to destroy the prostate tissue and destroy the cancer cells. In doing so, it can impact blood vessels that surround the prostate. It induces Ischemia which is trying to limit the blood flow to certain areas and that's how it induces cell death to the tissues. In that instance then, the prostate may become a little softer in different areas, but typically we do see it also become firm as it somewhat hardens up after radiation therapy. It can vary in that sense. Typically, patients would not know in terms of how their prostate feels or what to describe it as like a mushy prostate. A lot of that is based on how the digital rectal exam feels in terms of what that prostate consistency and texture is like.

Bearse: We also talked about the CyberKnife treatment. Is there a gleason grade associated when using this type of treatment?

Gandhi: From a gleason standpoint, typically you can be a candidate for any of these treatments from a CyberKnife. It's really trying to do some focused therapy to the prostate. Usually, it's utilized for low risk/intermediate risk. It can be utilized in high risk patients as well, but they typically may require additional therapies, what we call multimodal therapy. Most of the instances that we utilize it would be in a low risk or an intermediate risk patient population which typically varies from gleason 6 up to 7. With some rare instances in the 8s, but once it's into the 8s, 9s, 10s, you may be looking at more of a multimodal therapy where you may require some extended treatments to just try and reduce your risk of cancer recurrence.

Bearse: Jay Jay mentioned that he had multiple biopsies. Could you explain why men might need more than one biopsy?

Gandhi: I think that's a common thing. We have a lot of patients who we've seen who have had multiple biopsies and they're like ‘how much prostate is left for you to even biopsy.’ Honestly when we think about a biopsy, it's a very thin sliver of tissue that we take out. The analogy I always give is: if you take an orange and you insert a toothpick into that orange that's about the size of the sample you're taking out. Even if you inserted 12 toothpicks into an orange, you still see there's still plenty of orange. It's not like you took a large piece out of that orange and that's

similar to what a prostate biopsy is. It's rather commonplace that men may require multiple biopsies. I do think that trend is decreasing as the utility of MRIs has really increased.

The American Neurological Association has come out with revised guidelines over a year ago stating that all men should receive a prostate MRI prior to any biopsy, whether it is their first prostate biopsy or a subsequent repeat prostate biopsy. The benefit of an MRI is to truly assess the prostate to see if there's any abnormal areas. If there's any abnormal lesions that we need to try and target and focus, it has led to improvements in biopsy techniques. Rather than becoming a random sampling of the prostate, we're actually able to target specific areas that may have a higher degree of suspicion for prostate cancer. I do think that the number of repeat biopsies for diagnosis is likely to go down as MRIs increase.

However, there are men who are also on active surveillance and they do get repeat biopsies as well. Typically every one to two years, possibly longer depending how long they've been on surveillance monitoring if their prostate cancer becomes reclassified or is considered to be progressing before they transition to treatment options.

Bearse: I want to talk about recurrences. Are recurrences for prostate cancer common for patients?

Gandhi: Prostate cancer as we know typically is a slow growing disease process. The benefits to early detection is to be able to catch it at a time where it is slow growing. The chances for cure are quite high. You're talking about greater than 95, possibly even up to 99-100. The importance of early detection is critical. Now, this also correlates with gleason score family history, all these different risk factors in determining a patient's risk for prostate cancer recurrence.

As we see someone who has a higher gleason score somewhere in the 8s, 9s or 10s range, they tend to have a higher risk of prostate cancer recurrence and will require more therapy. A lot of times we would like to institute additional therapy initially to try and reduce that risk of cancer coming back versus someone who may have a low risk cancer of a gleason 6 or an intermediate risk as a gleason 7 who may have a lower risk of prostate cancer coming back. They might not require as much treatment up front because their risk already is low for recurrence.

Bearse: Thank you to Doctor Nilay Gandhi and Twisted Sister guitarist Jay Jay French for joining us today. We have much more to discuss with both of them in the next episode, but until then I'm your host, Jamie Bearse. Thank you for listening.

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