Prostate Cancer, Day 4,782 – Doctor Discussions

As my PSA levels rise, I'd like to know when it's best to get a PSMA PET scan and what type of cancer treatments lie ahead.

December 28, 2023 By Dan Zeller

I've had conversations with my radiation oncologist and my urologist this week.

UCSD Radiation Oncologist Discussion

The conversation with the RO was via email, which was fine by me. I'm thankful he takes the time to get back to me. In a nutshell, he said:

- We're on the verge of needing to do a PSMA PET scan.

- We should get the PSMA PET scan before any ADT.[1]
- If PSMA PET shows limited site(s) of recurrence, SBRT radiation may be an option to "ablate the larger cancer deposit and work in concert with ADT."

His recommendation was to get the PSMA PET scan now or to wait one month until early January 2024 and take another PSA test. If it remains steady, "we are good," but if PSA rises again, it would be time for a PSMA PET scan.

I'll let him know it took me two months to get my first PSMA PET scan at UCLA after speaking to the scheduling office, so getting it "now" may not be an option.

One other thing I need to nail down is where I can get the scan done again. When I had it in November 2021, the only two facilities in the U.S. that were approved to do the scan were UCLA and UCSF. Since then, far more facilities are capable of doing it, I believe including UCSD.

VA Urologist Discussion

Preparing for the meeting today, I put together an outline of things I wanted to discuss:

- PSMA PET Scan
    - If the VA would cover the cost this time.
    - If there's a difference in the tracers used (Ga-68 versus PYLARIFY® (piflufolastat F 18)
- ADT and the timing
- Whether they prefer a sequential or combination approach (e.g., include chemotherapy with ADT).
- Getting a medical oncologist who specializes in prostate cancer involved in the case.

But once I got there, I was definitely off my A-game for some reason, and the conversation was one of the weirder, more disjointed conversations that I've had with a VA urologist.

First, he was a new (to me) urologist and he entered the exam room a bit like a bull in a China shop. He didn't introduce himself and just started out with, "I looked at your PSA and read your email. What questions do you have for me?" Not even so much as a, "Sorry to see your PSA increase after SRT." That threw me off right there.

It was a bumpy conversation, but we eventually talked about most everything on my list. I'll save the bit about the scan for last.

Interestingly, he seemed to downplay spot radiation if lesions are found during a scan and was more focused on starting androgen deprivation therapy as the next course of treatment. But he wouldn't start it until after a scan was completed. He did say under certain specific circumstances, spot radiation may be helpful.

In the discussion about sequential versus combination treatments, he said that they would do a combination. I asked if it would be ADT and chemotherapy, and he said no. It would be ADT and antiandrogen therapy in combination using Eligard for the ADT and one of the following:

- Enzalutamide (Xtandi)

- Abiraterone (Zytiga)

- Apalutamide (Erleada)

I asked about chemotherapy with ADT, and he said that the antiandrogens have taken the place of Docetaxel (Taxotere), which I thought was an odd statement from my limited knowledge. I believe that Taxotere is still very much a treatment option used later in the progression of the cancer. I need to dig into that more.

Concerning shifting my case to a medical oncologist (MO), he said that would happen on its own, as he wasn't allowed to prescribe the antiandrogen drugs. The MO would also know how to better manage the side effects of the combined therapies.

Now, for the kicker part of the conversation…

He agreed that a PSMA PET scan was the best way forward but—and even he disagreed with this—the VA protocol is to have a bone scan first. The protocol said that, if a bone scan was negative, then a PSMA PET scan could be authorized.

He assured me that, at my PSA level of 0.33 ng/mL, the bone scan would, in fact, be negative. (Doing a quick Dr. Google search, it appears that bone scans start to pick up lesions when the PSA is over 20 ng/mL. Yep, 0.33 vs. 20.

So getting my soapbox and editorializing a bit here… It makes zero sense to get a bone scan in my present circumstances. None. The VA can be very slow to catch up with the times in certain circumstances, and this happens to be one of those times. It just seems to be a waste of time and resources when we already know that the bone scan isn't sensitive enough to pick up anything at my PSA level. But I'm not sure I'm up for "fighting city hall" to try and get the PSMA PET scan out of the gate.

On a positive note, the VA apparently can now do the PSMA PET scan according to the doctor.

I have to admit that I'm toying with the idea of using my Medicare coverage and going outside the VA for the PSMA PET scan and skipping the VA bone scan altogether. I need to dig into that and see how that would work and how quickly that could happen.

I just want to make sure that I'm not shooting myself in the foot in the process—the VA has to authorize community care in advance for them to continue to cover the costs. I don't want them to say, "Hey, you chose to go outside the VA system, so now you can pay for all the tests and drugs." I know Medicare would pick up a good chunk of the costs, but I may be on the hook for more than I

bargained for.

The urologist thought the bone scan could be scheduled pretty quickly and, if that's the case, that may put me closer to a PSMA PET scan faster than if I try to go outside the VA and create new relationships with new providers (although I think my radiation oncologist at UCSD may be able to assist me in ordering one and getting it scheduled).

We ended the conversation with him saying that we'll do another PSA test in three months. That surprised me a bit given its rapid rise over five weeks. "We know it's going to increase," he said, but he did offer to retest in six to eight weeks. I don't think we ever landed on a firm answer, so I need to chase that down.

In a way, though, it's probably more important to get the scan(s) done first, and tracking the PSA is secondary to that. Does it really matter if we retest PSA in eight weeks versus twelve weeks? I doubt it.

I left the meeting without:

- A date to have the bone scan.
- A follow-up date with the urologist (dependent on scan results).
- A date for the next PSA test.

Sounds like a productive meeting to me.

Istock

One other thing that happened today, which was quite unusual for me, was that I was far more nervous going into it than I should have been. I don't know what was up with that. I had difficulty articulating my thoughts, and my hand was shaking ever so slightly as I was taking notes. That freaked me out even more. I guess the emotions associated with this new chapter have been a bit more than I expected.

When the meeting was over, I sat in the waiting area for a good ten minutes to just decompress and to scribble down a few more notes while the conversation was fresh in my mind.

Once I calmed down, I went to the Nuclear Medicine department to try to schedule the bone scan, but the scheduler was away and the guy staffing the desk wasn't familiar with the process. I'll be back there tomorrow morning for another test, so I can try scheduling again when I'm there tomorrow.

I'll keep you posted.

1. This aligns with what Dr. Scholz says in this video. Taking ADT before the scan may reduce the size of the cancer to the point where the scan can't pick it up. https://youtu.be/CBILHS0FJfk?si=zaoHCOkm-mWOmdyz&t=525 ↩

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