Prostate Cancer, Day 5,616 – Ugh.

A massive disconnect during a talk with his doctor leaves prostate cancer blogger Dan Zeller feeling like he was punched in the gut.

March 31, 2026 By Dan Zeller

As soon as I hung up the phone with the doctor yesterday, I started memorializing our conversation in Google Keep while waiting for my turn in the barber's chair, and that was the outline I used for last night's post about the conversation.

As I said last night, I had planned on documenting the conversation in an email to the doctor this morning. I drafted what I thought was an accurate, reasoned response but, before I was going to send it, I wanted to see if I could get his take on the conversation in my patient notes. I logged onto the patient portal and found his notes from the conversation.

Apparently, the doctor and I have had a massive disconnect.

He mentioned our discussion about Axumin scans, saying, "that this is not recommended at this time given prior negative PSMA PET imaging and the limited likelihood that Axumin would provide additional clinically actionable information."

He also referenced our discussion about Pylarify scans, saying, "he recently underwent PSMA PET and that repeat advanced imaging would not be expected to change immediate management. Will review timing/appropriateness of repeat PSMA-based imaging if PSA continues to rise."

He closed his comments with a recommendation to see Hematology/Oncology.

It was like a sucker punch to the gut—I had a genuine physical reaction to reading his notes.

This tells me two things.

First, he is not convinced that there is such a thing as a PSMA-negative patient for whom PSMA PET scans won't work. That view is reinforced by his comments yesterday that he was confident my cancer expresses PSMA. In his mind, the 68Ga-PSMA-11 PET scan is definitive in its findings.

Second, it tells me that he isn't pursuing any alternate imaging at all. Just let my PSA continue to increase and try again with another PSMA PET scan.

Needless to say, I discarded my draft e-mail to him, stepped away for most of the day, and have

just been trying to process how to proceed. Of course, I'll re-write my email to him politely highlighting the disconnect between our versions of the conversation.

I wish I could understand his reluctance to believe that I may be PSMA-negative. A quick search last night gave me a handful of papers from reputable organizations on the topic:

> The clinical characteristics of patients with primary non-prostate-specific membrane antigen-expressing prostate cancer on preoperative positron emission tomography/computed tomograph
>
> Finding Metastatic Prostate Cancer that Doesn't Make PSMA
>
> The Blind Spot of Prostate-Specific Membrane Antigen Positron Emission Tomography Staging? Intraductal Carcinoma of the Prostate Is Overrepresented in Patients With No Uptake Pattern on Prostate-Specific Membrane Antigen Positron Emission Tomography and High-Grade Prostate Cancer
>
> The oncological characteristics of non-prostate-specific membrane antigen (PSMA)-expressing primary prostate cancer on preoperative PSMA positron emission tomography/computed tomography
>
> Normal Variants, Pitfalls, and Artifacts in Ga-68 Prostate Specific Membrane Antigen (PSMA) PET/CT Imaging

Of course, there's a lot of gobbledygook that goes way over my head in those papers, but the common theme is that PSMA-negative patients do exist and that affects imaging. The only possible distinction that I've come up with from briefly skimming those papers is that more aggressive cancers seem to express more PSMA than less aggressive cancers. Maybe the doctor could confirm that or educate me.

Of course, the Prostate Cancer Research Institute has a video on this very topic:

https://www.youtube.com/watch?v=XXjJPJczIrU

What's next? I'm thinking that I'm going to pursue two parallel paths, one within the VA and one outside of it. Both will likely take weeks if not months to pursue. (I'm not panicking about this, but I also don't want to keep kicking the can down the road without doing anything to guide our decision-making, especially seeing as my PSA doubling time seems to be shrinking.)

Within the VA, I'm going to:

1. Write the urologist and let him know that I came away from our phone call with a completely different take.

2. Push to get the appointment with Oncology and hope to enlist them as an ally in trying to get an alternate scan sooner rather than later. In the in-person meeting, the urologist seemed to be deferential to their opinion.

3. If neither of those results in any action, I'll meet with the patient advocate at the VA and see if that can break the log jam either within the VA or by allowing me to gain community care outside of the VA.

Outside the VA, I'll look at:

1. Identifying what's needed to become a patient at UCSD. It may not require much, as they did my salvage radiation therapy almost four years ago.

2. Try to set up an appointment with the medical oncologist that the VA consulted when we talked two years ago.

3. Get his take on alternate imaging.

I will tread very carefully because I don't want to screw up any eligibility for care within the VA by going outside the VA or create confusion as to who is really taking the lead on my care. That's why it's really best that, if the VA can't or won't pursue additional screening, that they are the ones who initiate the request for community care. It's something I need to research.

So that's how I'm going into the weekend. How about you?

Be well.

This post originally appeared March 27, 2026, on Dan's Journey Through Prostate Cancer. It is republished with permission.
