

Merel Grey Nissenberg

Changing Screening Recommendations

Ms. Merel Grey Nissenberg, a California attorney specializing in medical malpractice cases, is the President of both the American-based National Alliance of State Prostate Cancer Coalitions (NASPCC) and the California Prostate Cancer Coalition (CPCC).

Prostatepedia spoke with her about the recent proposed changes to the US Preventive Services Task Force (USPSTF) recommendations on screening.

How did you become involved in prostate cancer advocacy?

Ms. Merel Grey Nissenberg: I'm a trial attorney. I handle medical malpractice cases.

Obviously, I don't have a prostate. I don't have anybody in my family who passed away from prostate cancer, but I'm very interested in prostate cancer and in cancer advocacy.

In my law practice, I've handled a lot of prostate cancer cases with inexcusably late diagnoses. Just shabby care. A lot of those clients have passed away because of that.

In 1994, I handled a case that had a surgical oncologist as one of our experts. He recommended that I start

working on the California Division of the American Cancer Society's Prostate Cancer Task Force, which I did.

I then went on to co-chair the task force. In 1997, there was a California-wide American Cancer Society meeting on prostate cancer. We thought it would be great to have a statewide California coalition for prostate cancer. Everybody said we couldn't do it because California is too big. We heard that challenge. The California Prostate Cancer Coalition is now 20 years old!

Was this the first American statewide prostate cancer coalition?

Ms. Nissenberg: At that time, Pennsylvania had a coalition and Massachusetts had a fledgling coalition. A few other states were just starting coalitions.

In 2001, I went to a meeting with 20 state leaders in Washington, DC, at the former National Prostate Cancer Coalition (NPCC.) NPCC is now ZERO. We wanted to see how the states could help their organization—and how NPCC could help the states with *their* missions.

At that meeting, I met a lot of people from other state coalitions. I said I'd like to set up coalitions in all 50 states. Jan Marfyak, a prostate

cancer survivor who was co-chair of the Pennsylvania coalition at the time, thought that was a great idea. Together, we started raising money to set up state coalitions.

In 2004, we decided to set up a national alliance, an umbrella organization, which would allow states to network with each other and to share best practices. This is now the thirteenth year of the National Alliance of State Prostate Cancer Coalitions.

Our original goal was to make prostate cancer a national healthcare priority by becoming a collaborative force that developed and mentored state prostate cancer coalitions.

In 2014, we added two core priorities: awareness and education, and public policy advocacy. To address awareness and education, we created a guide on prostate cancer screening aimed at patients and primary care physicians alike. (See <https://tinyurl.com/nycvrr6>).

How have the United States government's recommendations on prostate cancer screening changed?

Ms. Nissenberg: When I first got involved with prostate cancer advocacy, the recommendation was inconclusive whether you should screen or not. In fact, in our work, we

use the word 'testing' because the term "screening" is so controversial.

In 2012, which was the most recent USPSTF Recommendation, the US Preventive Services Task Force announced a straight across-the-board D recommendation: do not screen. Most physicians saw the "D" at the top of the page and never read beyond that.

But then we went back and looked. In the middle of the middle sections of the recommendations, in the Clinical Consideration section and in the Reply to Public Comments section, the Task Force clearly says that if a man wants to have an informed discussion about prostate cancer, his physician must—this is mandatory language—have that discussion with him. It is then the patient's decision based on his own values and preferences whether or not to get tested. It was buried in the guidelines, but it's there.

I know a lot of men have since gone for their regular physicals and have not been offered PSA testing, even though they're getting blood drawn for other things. The issue of prostate cancer screening is not brought up. They're not even offered digital rectal exams (DRE).

There was a huge outcry after the 2012 Guidelines became final; they did not take into account your family history, if you're African-American, or if you have been exposed to Agent Orange or any other type of banned chemicals. (Agent Orange is a huge risk factor for Vietnam veterans.)

The 2012 recommendation scared men away from asking for testing. Later the California Prostate Cancer Coalition and the American Cancer Society worked together briefly to get some language into the ACS guidelines that we could both live with. We did not like the way ACS

used the phrase *potential* benefits and harms instead of *potential* benefits and *potential* harms. (The word "potential" only referred to the benefits, not the harms.) It made the benefits only potential, but the harms certain.

Precision in language is important...

Ms. Nissenberg: Exactly. But the USPSTF proposed changes to the guidelines in April of this year; it would still be a D recommendation for men 70 and over (with no regard to life expectancy), but a C for men 55 to 69. They're recommending that a man speak with his physician and that the physician offer the man an informed discussion about prostate cancer testing.

Based on the 2012 guidelines, physicians didn't have to bring up testing at all. They were completely relieved of the responsibility of bringing up prostate cancer testing. Physicians felt that legally they didn't have to discuss testing with men.

An informed discussion is not the physician telling you why you don't want to be tested. Your physician is supposed to discuss the risks of being diagnosed with a cancer that doesn't need treatment. He or she should also discuss the benefits: if you have an aggressive disease, early detection is critical.

Men need to know that this is their decision to make, based on their preferences and values. It's not for someone else to say that you don't need to know about this.

I've dealt with cases in my law practice in which the doctors actually note in medical records that the patient wants a PSA. "Patient is worried about prostate cancer." And still some doctors have refused to test. Some of those patients are dead now.





People tend to trust whatever the physician says.

It's that old hierarchal relationship people have had with their doctors.

Ms. Nissenberg: Right. They just tend to think he or she has this superior experience, training, and expertise, so if the physician says don't worry, the patients won't worry.

But, as I said, physicians haven't even been bringing testing up—and have felt legally justified in not doing so.

The way I see it is that you have to educate, not just the primary care doctors, but also men—prospective patients—so they know to ask about prostate cancer screening. You can't ask for an informed discussion about something you don't know exists. We need to educate both groups.

So from the D recommendation of 2012, the proposed guidelines now say that physicians should discuss the potential benefits and risks associated with screening with men 55 to 69.

But the NASPCC and the CPCC have problems with the new proposed guidelines. First, why start at age 55? We advocate that a man get a baseline PSA in his early 40s. This gives a risk assessment; you can then personalize follow-up.

If you're at low risk based on your PSA reading, you don't have to come back for retesting for another five years. (No one is suggesting that men get yearly PSA tests.)

If you're at intermediate risk, you get retested every one to two years, depending on your other risk factors.

Men at high risk would obviously need immediate follow-up.

Even the Task Force itself acknowledges in the Frequently Asked Questions section of the new proposed draft guidelines that sometimes you don't see a benefit to screening for over 10 years. Sometimes 10-15 years. If you wait to get baseline tests until men are 55, you lose an opportunity to prevent some of them from developing metastatic disease.

Another change in the recommendations is that the Task Force now discusses active surveillance. The guidelines say that there are men who will choose active surveillance, so those men will not be overtreated by definition. But the guidelines did not also acknowledge the fact that we now have urine, blood, and tissue markers that can help determine whether or not a man is at risk for aggressive disease. Why worry about overtreatment if a man is diagnosed, but not acknowledge the availability of biomarkers to select those at high risk for clinically significant prostate cancer?

Lastly, NASPCC and CPCC believe that Vietnam veterans and others exposed to Agent Orange should be included in the Task Force definition of a high-risk group (that currently includes African-American men and men with a family history of prostate cancer).

We do applaud that the Task Force is now finally openly talking about informed decision-making.

It's important to remember that not everyone who is tested will be overtreated. (I don't believe there is such a thing as overdiagnosis.) Diagnosis is just information.

You can choose not to be treated once you have the information.

Ms. Nissenberg: Exactly. You wouldn't tell a woman, "You don't really want to know if you have breast cancer, dear."

After a certain age, women get mammograms yearly:

Ms. Nissenberg: Exactly. Physicians take that choice away from men.

We distribute our decision-making guide (see <https://tinyurl.com/nycvrr6>) to physicians as well as patients so that they know which questions the patient is going to ask. (Men aren't going to be coming in with 500 pieces of paper from the Internet.)

In the guide, we talk about things like baseline PSA, the importance of family history, ethnicity, and exposure to Agent Orange. Questions like: If I have a biopsy and it reveals cancer do I necessarily have to have treatment? What is active surveillance?

Good, basic questions-and-answers.

Why are they revising the guidelines now? Because of the outcry in the prostate cancer community? Or is this just part of the normal cycle of revision?

Ms. Nissenberg: It is part of the normal cycle of revision. The outcry probably helped precipitate it, but this is just their normal timeframe.

What do you feel are the greater implications of the guideline changes?

Ms. Nissenberg: The implications are that more men will hopefully be tested. More men will have that conversation and make their own informed decision about whether they want to be tested or not. The changes to the guidelines will raise awareness at the very least.

The changes are a good start, but we've got to go further. 

