

From the Desk of the Editor: A Million Faces: What Prostate Cancer Awareness Means to Me

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Prostate cancer is something that touches most of us, at least indirectly, at some point in our lives. It is the most common cancer in American men, and the second leading cause of cancer death in this country. Our continued efforts as clinicians, researchers, patients, family members, loved ones, and advocates are critical if this is to change. And to me, prostate cancer awareness means that we must recognize the many ways people feel prostate cancer, and know that we can make a difference in at least as many ways. Prostate cancer awareness means recognizing the millions of faces of this disease, and doing what they need to change the status quo.

Prostate cancer awareness to me is Mr. Harrison. When I met him, he was a 71-year-old healthy man, likely with decades of life ahead of him. This was his belief too until he heard the words “you have metastatic prostate cancer.” He was stunned. He and his family were all about prostate cancer awareness, and he was the poster child of caution when it came to his health. He had been getting PSAs with his PCP every year until his PCP stopped performing PSA screening tests and DREs because of the D recommendation in the USPSTF guidelines. About 2 years after this, some back pain led to a scan that demonstrated widespread metastatic disease that was diagnosed as prostate cancer. He came to see me and started on his continued journey with this disease.

Prostate cancer awareness is spreading the word about PSA screening. Mr. Harrison isn't unusual, but he should be. Since the USPSTF D recommendation regarding caution with PSA screening, I have seen numerous men with a similar story. It is up to each of us to counsel our friends and family that this previous guidance has been revised, at least

to a C, and further research has been recommended. As clinicians and researchers, we must continue to optimize our screening assays and get the right treatments to the men who need them, avoiding surgery and radiation in men with low-risk cancer that will never threaten their lives. Mr. Harrison is a reminder to me that prostate cancer awareness requires vigilance on the part of patients and their loved ones, speaking up if they want to talk about screening, and ensuring they get testing if it makes sense for them.

Prostate cancer awareness to me is Mr. Orlen. I met him when he was 68 and had been on the prostate cancer journey for a decade already. He had undergone a radical prostatectomy with the esteemed Dr. Catalona at Northwestern University, but it had come back a few years later. He went on to salvage radiation and treatment with ADT followed by abiraterone, then moved to Nashville where I met him. We worked to get him treatment after treatment over several years and found ourselves near the end of our FDA approved options. He tried a clinical trial with our urologists and came back to me. Radium was approved and available at this point, for nearly a year, but issues with concerns over compounding led my institution to hesitate in providing it. Luckily, persistence on the part of my colleagues and me finally was successful, and we were able to offer it just as the clinical trial failed him. Mr. Orlen received radium, then olaparib, then enrolled on two additional clinical trials before he finally enrolled in hospice and passed away, nearly 3 years after receiving radium. He felt well, even on hospice, due to our efforts in maximizing the quality of life each day, knowing that these days were not possible only a few years before.

Prostate cancer awareness to me is ensuring access to therapies to all men, and engaging every man with prostate cancer in research protocols that can move our field forward. These efforts are not just for men who live in urban areas near large academic centers of excellence. A majority of men with prostate cancer are treated in community centers, and many never think about partnering with academic or private institutions in their areas that may offer clinical trials or treatments not

available in smaller centers. We must all continue efforts to ensure that community urologists and medical oncologists hear about the amazing advances being made and feel comfortable providing these treatments to the men they care for. Academic physicians must make an effort to be available to their colleagues in the community, and pledge to work together with all of the members of a patient's clinical team to provide access to clinical trials and excellent local care. It literally takes a village, and that starts with us.

Prostate cancer awareness to me is Bill Morgans. I have known him since before I could talk and loved every minute I had with him. Bill was my grandfather, who was diagnosed with prostate cancer about a month after I started my first faculty member position with a focus in GU oncology and prostate cancer research. For as long as I had known him, my grandfather disliked physicians and hospitals, preferring to pursue natural and holistic methods to improve his health. Now that he was in his 80s with a diagnosis of high risk localized disease and a PSA in the hundreds, I appreciated that he was open to talking about his preferences for treatment, and what he would and would not do. After initial treatment with bilateral orchiectomy (the natural option), he felt well and continued to live independently. Within a few years, however, dementia that had started to set in before his diagnosis was more limiting, and he moved across the country to live with my aunt. I heard when his disease became castration-resistant (still non-metastatic) after his move and got a call in the fall of 2017 when his disease progressed to widespread metastatic disease, urinary outlet obstruction, bilateral hydronephrosis, recurrent urinary tract infections with subsequent bacteremia, and intense pain. Coupled with his advanced dementia, and his clearly stated wishes, he was admitted to an inpatient hospice and passed away with his family around him within a few days.

To men, prostate cancer awareness is recognizing that every man deserves the right to forge his own path, even if data and years of medical training tell us what is "right". As clinicians and loved ones, we must understand that it is our duty to guide, but not our right to dictate

the way things should go. Although personal values, preferences, and beliefs may challenge our understanding and be flatly wrong if our goal is solely to extend life, we must recognize that the goals of our patients come first. Quality of life and maintaining a sense of self truly is the most important thing to many men, it this must be respected. When my grandfather passed away this fall at 91, he did so knowing that he had lived an amazing life, loved until his last breath, and had a family that would adore him forever. This is what I wish for any man whose life is taken by prostate cancer until we make death from this disease history.

Prostate cancer awareness to me has many faces and many meanings. Every day that passes is an opportunity for us to make a difference in reducing death from disease, prolonging life, and making lives lived with prostate cancer better. Until there is no death or suffering from prostate cancer, I think of this month as one of incredible importance and urgency, and one whose meaning and mission do not stop on September 30. If we aim to make this a world that is past needing a prostate cancer awareness month, we must all do our parts. The time is now.

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