Last May, the U.S. Preventative Services Task Force triggered a firestorm of debate when it recommended against the prostate-specific antigen (PSA) test as a screen for prostate cancer.

By discouraging PSA screening, they hope to diminish the harm caused by prostate cancer over-treatment. Unfortunately, they also risk delaying its diagnosis.

In her editorial responding to the controversy, Task Force chair Dr. Virginia Moyer summarized the committee’s findings with this sentence: “We can do better.” We at the Prostate Cancer Research Institute (PCRI), while disagreeing with the Task Force’s “D” rating of PSA, do agree with Dr. Moyer’s conclusion: We can, indeed, do better.

We can, for instance, do a better job of educating men on the optimal use of the PSA test. If men simply pause to think before rushing into a biopsy, they can:

1) Better determine the need for biopsy by determining the aggressiveness of the tumor with the PSA doubling time; and
2) Improve biopsy accuracy by locating the tumor beforehand with a multi-parametric MRI.

This is valuable information that improves biopsy outcomes and decreases the cost of care by improving the use of biopsy, the very things the USPS Task Force has asked us to do.

However, all this recent controversy gives people an excuse to ignore a disease that affects one in six men and causes the death of 28,000 every year. The subject of prostate cancer already makes men uncomfortable. The controversy over the PSA test gives them one more reason to avoid a well thought-out action plan for their prostate health and screening.

The PCRI encourages men to learn about PSA screening in consultation with their physician. When PSA screening detects elevated levels, be prepared for this consultation by using the PCRI Helpline and other educational programs before proceeding to biopsy and treatment.

PCRI supports Rep. Marsha Blackburn in her efforts to pass HR 5998, a bill that would help Dr. Moyer’s team resolve controversies like this before they begin. The proposed bill would increase the accountability and oversight of the Task Force (to learn more about the bill and read the full text, visit http://www.opencongress.org/bill/112-h5998/show). You can take a position with us by sending me an e-mail at dfoster@pcri.org.

We at the PCRI encourage PSA use with wisdom, patience, education, healthy behaviors and careful health care choices. The PCRI stands in agreement with Dr. Moyer that together, we must do better.

Never too young for prostate cancer:

A Couple’s Path to Education and Empowerment

By Rikki and Terry Robinson

I distinctly remember our lives before cancer.

Last year, we spent a beautiful October afternoon on the waterfront, celebrating my grandmother’s 80th birthday. Life felt good. I thought it would be a great time to get my family together to snap a photograph.

Looking back, I realize I was oblivious to the turn of events about to take place in our lives. Little did I know, our seemingly peaceful world was about to be turned upside-down and rocked at its core.

In an instant, our lives began to change. My mom and I were sitting by each other on the couch when my husband, Terry, walked in and sat between us. He explained that he had received a phone call from his physician regarding the results of blood work he had submitted the day before. She told him his PSA blood test was elevated at 17.2, and that he would need to see a urologist. She explained that it didn’t necessarily mean anything serious, but definitely warranted further investigation. Terry looked at me and said, “This could mean Prostate Cancer”. My first thought was, my husband is going to die. I saw our lives with our young children flash before my eyes.

I didn’t really know much of prostate cancer at the time. Coincidentally, I had read an article about the PSA screening controversy about one month prior. The article itself was interesting, but I quickly tucked it away mentally, thinking to myself, why would I need to know about prostate cancer, my husband was only 45 years old.

We saw Terry’s urologist, a great doctor with a calming disposition. He explained that a PSA of 17 was high for a man Terry’s age. It could mean cancer, or it could be something else. He performed a digital rectal exam (DRE), and we received a bit of good news: he didn’t feel a lump, but thought the prostate felt a tad firm, which may be suspicious. He gave Terry’s PSA two weeks to come down.

Two weeks later, Terry went back for a second PSA test. His doctor called him with the results, and explained that Terry’s numbers didn’t go down - in fact, they went up to 18 - and he would need a biopsy. Terry called me to break the news, and I broke down and cried. At this point, nothing was going our way.
While we waited on biopsy results, I began an unending search to educate ourselves on all things prostate cancer. I was up all day and all night to the point of insanity. I couldn’t stop. The first thing that struck me was Terry’s PSA. Some organizations state that the normal range for a man of his age (45) was 2.5 and below. Terry’s PSA of 18, if proven to be prostate cancer, could in fact be very serious. At times, this new reality felt like more than I could bear. Still, I pressed on.

**Faith Kicks In**

It’s strange, but I had a deep knowing that my husband had prostate cancer. We couldn’t reconcile his elevated PSA, and at that point knew too much about the disease to convince ourselves otherwise - but beyond that, we knew.

We also knew, however, that in the darkest moment of our lives, and in spite of our immense fear and anxiety, God was there. Every second of every day, both of us felt God’s presence stronger than any other time in my life, and it provided me with a peace beyond comprehension.

We learned that prostate cancer tends to be non-aggressive, slow-growing cancer with a majority of men being diagnosed with low-risk disease. Often, men in this category can opt to watch their cancer, rather than treat it right away. For the men that fall into the category of intermediate or high-risk disease, prostate cancer can behave very unpredictably, be more aggressive, and require treatment. Terry’s PSA continued to worry us. We prayed that his cancer was treatable.

It was two days before Christmas when we learned Terry had cancer. He called me on the phone, and his voice sounded sad and empty. He painfully uttered the words, “I have cancer”. We both sat in silence for a moment. We were shaken and scared to death.

High-risk disease is a Gleason 4+4, and Terry’s pathology showed a Gleason 4+3, which was intermediate risk [1]. In that moment, I realized the PSA test may have saved his life. Like a red engine light in a car that flashes when something needs to be checked, it didn’t indicate cancer, but rather, pointed out that something wasn’t quite right and that we needed to investigate further. The test provided us with very important information about my husband’s body, and afforded us the opportunity to do something about it. Although we didn’t catch Terry’s cancer as early as possible, we did catch it just in time. For this reason, we support a baseline PSA test for all men starting at age 40.

There is no “one size fits all” treatment for prostate cancer. Men who choose to treat their cancer usually need surgery. We learned that prostate cancer tends to be a non-aggressive, slow-growing cancer with a majority of men being diagnosed with low-risk disease. Often, men in this category can opt to watch their cancer, rather than treat it right away. For the men that fall into the category of intermediate or high-risk disease, prostate cancer can behave very unpredictably, be more aggressive, and require treatment. Terry’s PSA continued to worry us. We prayed that his cancer was treatable.

Finally, some good news!

I met Terry’s surgeon in the waiting room, who said his surgery went great. I returned to my family in the waiting room and sobbed like a baby. Words cannot express the relief I felt in that moment.

Even better, Terry’s post-op pathology confirmed a 4+3 Gleason, with clear margins and negative lymph node involvement. His post-op PSA was undetectable, his surgery was a success.

**Life Moves Forward**

There is a stigma that comes with prostate cancer. Most men don’t want to talk about it, especially because it involves that part of the body. Couple that with someone so young, and the silence is deafening. We decided early on, not only would we be advocates and educators, but we would also be open about the side effects. Terry never felt ashamed. Our hope is that the next generation of men and women will use their voice to help raise awareness. Yes, there is much work that still needs to be done, and we lag behind other major cancer awareness campaigns. Still, we are hopeful, and can’t help but feel major breakthroughs headed our way in terms of medical research and social awareness.

Attitude is everything during the healing process. We managed to laugh quite a bit through cancer, probably to keep from crying. We even laughed the day Terry had to put on a diaper following catheter removal. He snapped a picture of himself in the doctor’s office with a big smile on his face. He was completely dry within six weeks of surgery.

Why would I need to know about prostate cancer? My husband was only 45 years old!

Terry’s doctor prescribed him Levitra as part of his penile rehabilitation plan. It didn’t do anything for us sexually at first, but we understood why. I guess it’s at this exact juncture couples get tripped up sexually. When you focus on the part of the body that isn’t working, you stay stuck right there, and hinder the healing process both physically and emotionally. The key for us was acknowledging sex as different, but not broken.

Even if a couple is stable, a mere lack of communication and poor understanding of the healing process and side effects can be detrimental to a marriage. We encourage all men and couples to talk openly and honestly about the issue first, to come up with a sexual rehabilitation plan beforehand.

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**To understand your prostate cancer risk category, including questions to ask your urologist, see the article in the August 2012 issue of PCRI Insights, titled Newly Diagnosed Prostate Cancer: Understanding Your Risk.**

1) NCNC Guidelines Version 3.2012 Prostate Cancer