PCRI welcomes new medical director at 2012 conference

PCRI would like to thank everyone who attended the 2012 prostate cancer conference in Los Angeles!

This year, we proudly welcomed medical director Dr. Dean Foster as the newest addition to our team.

Inspired by his personal prostate cancer journey, Dr. Foster has an ambitious vision for PCRI. To read more about Dr. Foster and his goals for PCRI as medical director, see page 7.

We are now taking orders for DVDs of the conference sessions, which are available with a donation of $150 or more. Please order yours today by submitting the enclosed coupon or calling the PCRI office at 310-743-2116.

For a recap of the 2012 conference, see page 8.
“Without continual growth and progress, such words as improvement, achievement, and success have no meaning.” - Benjamin Franklin

I agree with Franklin’s quote on success. It’s easy to pat yourself on the back when you hear praises from countless people.

The conference was a great success!

Words are easy to come by. But what action lies behind the words? Why was the 2012 conference more successful than in previous years?

It’s possible that this success was a result of adding more support group sessions to meet individual needs, or giving attendees the opportunity to ask questions directly of each speaker.

Or could it perhaps be attributed to the Saturday night gala, where attendees heard the inspiring story of our new medical director, and danced to the sounds of Motown by Jerry Peters and Friends? Or is it as simple as a staff and board of directors who are committed to going the extra mile for a prostate cancer survivor and his family?

XTANDI is a success!

The success of a new cancer treatment has the potential to help thousands of men with prostate cancer, where there may previously have been little hope. Dr. Shore’s article on XTANDI (enzalutamide) on page 3 shows progress and gives new hope for men who have castration-resistant prostate cancer.

The report from my last doctor’s visit was a success!

For a prostate cancer survivor, success comes in many forms. A decline in PSA, an intimate moment with a partner, a good laugh, an even better cry - these are all signs of progress in the journey of a prostate cancer survivor, as illustrated by Rikki and Terry Robinson’s story on page 17.

The PCRI is successful, and continues to experience growth and progress. Thanks to your generous donations, we have been able to add a medical director, Dr. Dean Foster, to lead us down the path of even greater success. Dr. Foster will guide us towards improved education, awareness, and research for prostate cancer; with new programs such as the Mentor Program to help educate support group leaders, and improvements to our website.

The real success of the PCRI, however, is you. Each one of you means something to all of us. It means something to educate and empower those of you who reach out to our Helpline, and to hear your stories. Because of you, our mission is permanently branded in our hearts.

Whatever you are able to donate means something to us. The PCRI staff takes your giving seriously, and is devoted to being good stewards of your generosity. Whatever you are able to donate means something to us. The PCRI staff takes your giving seriously, and is devoted to being good stewards of your generosity.

The saying “your success is our success” has never been more true. May you have a healthy, prosperous and successful holiday season and new year!

Michael Steinberg, MD
Director, Prostate Institute of America

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XTANDI (continued from page 3)

An increase in PSA level is a consequence of androgen receptor-driven genes in prostate cancer cells. The goal of hormonal cancer treatments in prostate cancer is to inhibit the action of the androgen receptor.

The androgen, testosterone, is synthesized primarily in the testicles (~90%), but is also synthesized by the adrenal gland, and by the prostate tumor itself. Patients who are on ADT have very low levels of testosterone in their blood. Despite these low (and sometimes even undetectable) blood levels of testosterone in patients with CRPC, the androgen receptor continues to be active in cancer-promoting tumor growth.

In patients with CRPC, prostate cancer cells adapt to low-circulating androgen levels, and continue to activate the androgen receptor by numerous mechanisms: mutations to make the androgen receptor more responsive to androgens or other steroids, increasing the number of androgen receptor molecules in the cell, and mutations that activate the androgen receptor in the absence of androgens. Additionally, it has been reported that prostate cancer cells can produce androgens themselves by alternate mechanisms [1]. Thus, treatments that directly inhibit the androgen receptor may be of value.

Anti-Androgens Bind to Androgen Receptors

Anti-androgens (such as bicalutamide and nilutamide) have been shown to bind to the androgen receptor and inhibit its activity, at least initially. This is called antagonism. However, these drugs have a much lower binding affinity for the androgen receptor compared to androgens such as DHT. In some situations, anti-androgens have been shown to have opposite effect, and may actually activate the androgen receptor (agonist activity) [3]. In cases like this, your doctor may stop your anti-androgen therapy as a form of treatment. This has been called anti-androgen withdraw response (AAWR), and has not been shown so far to be a problem with Xtandi.

Enzalutamide is a multi-acting androgen receptor signaling inhibitor.

Enzalutamide was specifically designed to overcome AR resistance common in CRPC patients and to avoid agonist activity [3]. It is the first and only androgen receptor inhibitor that targets multiple steps in the androgen receptor signaling pathway (Figure 1).

**FIGURE 1**

![Tumor Death](image)

- Enzalutamide inhibits nuclear translocation of AR
- Enzalutamide inhibits binding of Androgens to AR
- Enzalutamide inhibits association of AR with DNA

A = androgen AR = androgen receptor

XTANDI (continued from page 4)

In addition to strongly binding to the androgen receptor, enzalutamide inhibits the movement of the activated androgen receptor to the nucleus. For those activated androgen receptors that do get through, it inhibits binding of the activated androgen receptor with DNA, even in the CRPC patient [3]. In animal models, enzalutamide has been shown to decrease the growth of prostate cancer cells, induce cancer cell death, and reduce tumor size. Another plus is that it does not have androgen receptor agonist activity.

The recommended dose of enzalutamide is 160 mg taken orally, once a day, and can be taken with or without food. Enzalutamide is available as 40 mg capsules.

In clinical trials, corticosteroids (e.g., prednisone) were allowed but not required. Evidence for the anti-tumor activity of enzalutamide comes primarily from two clinical trials: a smaller open-label Phase 1-2 trial (NCT00510718), which determined the maximum tolerated dose by 34% of patients on enzalutamide and evaluated the antitumor activity, along with safety and tolerability [4]; and a large, randomized placebo-controlled trial that evaluated the efficacy and safety of enzalutamide (The Phase 3 AFFIRM trial, NCT00974311) [5].

In the Phase 1-2 trial, enzalutamide was found to have antitumor effects. This study enrolled 140 patients: 65 with no previous chemotherapy (chemo-naïve) and 75 who had previously received docetaxel (post-chemo). Groups of patients were treated with doses ranging from 30 to 600 mg per day. Percentage of patients with a 50% or greater decrease in PSA from baseline is useful measure of anti-tumor response. The percentage of responders among post-chemo patients was 51% and was 62% in the pre-chemo patients. Fatigue was the most frequently reported adverse event including 11% of patients who reported significant fatigue. In this trial, three patients (~2%) were reported to have had a seizure, all of whom took enzalutamide above the maximum tolerated dose of 240 mg/day. The FDA-approved dose is 160 mg/day.

In addition, randomized, placebo-controlled trial (the AFFIRM trial) included men with CRPC who had previously been treated with docetaxel.

Eight hundred men took 160 mg of enzalutamide once a day and 399 took placebo. Patients in the trial were required to continue taking an LHRH (luteinizing hormone-releasing hormone) agent or to have had orchectomy. The median duration of treatment with enzalutamide was 8.3 months, while with placebo it was 3.0 months. Patients were allowed, but not required, to take prednisone.

In the AFFIRM trial, the median overall survival was longer on enzalutamide compared to placebo treatment: 18.4 months for patients taking enzalutamide compared to 13.6 months for placebo [Hazard ratio= 0.63, P<0.001] [5].

The most common side effects reported in patients receiving enzalutamide in the AFFIRM trial were fatigue (34% enzalutamide vs 29% placebo), diarrhea (21% vs 18%), and hot flashes (20% vs 10%). Severe side effects (grade three or higher) were reported by 45% of the patients taking enzalutamide and 53% of the patients on placebo. Serious side effects were reported by 3% of patients on enzalutamide and 39% of patients on placebo. There was no evidence of hepatotoxicity (liver toxicity) in either trial; in AFFIRM, liver function abnormalities were reported in 1% of the enzalutamide patients and 2% of the placebo patients, and all were mild to moderate in severity.

XTANDI has been associated with an increased risk of seizure. In the AFFIRM trial, five patients (0.6%) were reported to have had a seizure, whereas no seizures occurred in patients treated with placebo. Confounding factors may have contributed to the occurrence of seizures in several of these cases, including brain metastases, alcoholism, or the use of medications known to predispose a patient to seizure. When a patient experienced a seizure, enzalutamide was discontinued, and all seizures resolved. Based on data from the Phase 1-2 trial, the enzalutamide dose appears to be an important predictor of seizure, with a greater risk of seizure at daily doses higher than 160 mg. In the Phase 1-2 trial, no seizures were reported at daily doses ≤ 240 mg, whereas seizures were reported in one patient each at 360, 480, and 600 mg per day. Patients should discuss with their healthcare provider any conditions that may predispose them to seizures, and any medications they may be taking that lower the seizure threshold.

CONTINUED ON PAGE 5
androgen-sensitive prostate cancer. The treatment did not prove prostate cancer drugs, as well as the potential role of enzalutamide in earlier stages of both CRPC and castration-resistant prostate cancer (CPRC) to be a very promising therapy. Future studies should investigate both combination strategies with other antiandrogens and non-steroidal androgen inhibitors, as well as enzalutamide used alone.

However, prostate cancer did not stop with his father. On Dr. Foster’s 57th birthday, he received a phone call from his own physician, who told him that he too had prostate cancer. However, prostate cancer did not stop with his father. On Dr. Foster’s 57th birthday, he received a phone call from his own physician, who told him that he too had prostate cancer.

Given enzalutamide’s unique and multi-targeted mechanism of action, its once a day oral administration, avoiding further trials to evaluate the ideal sequencing and combination strategies to ensure safety while maximizing the potential efficacy of these new therapies.

REFERENCES


Acknowledgments: Editorial support was provided by Genentech, Inc.

By bringing patients and physicians together with the PCRI, Dr. Foster believes we can accomplish all of the above goals and help fulfill his personal motto: ‘We will stop prostate cancer!’

Watch Dr. Foster’s keynote address at the 2012 conference by ordering a copy of the DVD today.

Dr. Foster graduated from the University of California, San Diego in 1972 with a focus on molecular biology. He completed his medical training at the University of Southern California, and is an active fellow of the American Academy of Orthopedic Surgeons. While leading a group practice in the San Diego area, he specialized in reconstructive surgery of the extremities, including internally healing unstable pathologic fractures.

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2012 Prostate Cancer Conference

By Madhu Rajaraman, Senior Writer-Editor and Dean Foster, MD, Medical Director

Conference Attracts More than 800 Attendees

Order your DVD today!

PCRI would like to thank everyone who attended this year’s conference!

The 2012 conference was PCRI’s most successful yet, attracting more than 800 attendees from 38 states and seven countries. We are now taking orders for DVDs of the conference sessions, which are available with a donation of $150 or more.

We once again welcomed the University of Michigan’s Dr. Mark Moyad as conference moderator. Dr. Moyad, as usual, injected his trademark humor and energy into the sessions.

Low/Intermediate-Risk (Sky/Teal Shades)

Dr. John Blasko gave a talk on the Sky and Teal shades of prostate cancer, in which he explained that a big concern for men in these low and intermediate-risk categories is often summed up in the following question: To treat or not to treat?

For men with high-risk, relapsed and advanced disease, some form of treatment is almost always necessary. However, men with lower risk prostate cancer can often defer treatment in favor of watchful waiting or active surveillance.

Dr. Blasko differentiated between the two approaches, using the following distinctions:

Watchful Waiting: Characterized by no testing, and treatment only if and when cancer symptoms (such as bone pain) develop.

Active Surveillance (preferred): Characterized by periodic testing, with definitive treatment if progression is observed.

For men in the Sky and Teal shades who decide to pursue treatment, Blasko gave overviews of surgery and radiation options.

Surgery: Men have the option of robotic or non-robotic prostatectomy. In a robotic prostatectomy, which is computer-enhanced, the surgeon performs the procedure from a 3-D console with his or her hands placed inside devices that direct the movement of the instruments.

Avoiding cutting nerves is an important goal in surgery, in order to help prevent impotence.

High-Risk Prostate Cancer (Azure Shade)

Dr. Richard Lam of Prostate Oncology Specialists lectured on high-risk prostate cancer, or the Azure shade, which he defined as “localized cancer with a high likelihood of microscopic spread, and therefore relapse.” The Azure shade is also defined by the following characteristics:

- Normal CT and bone scans
- High-risk features (any one of the below)
  - PSA > 20
  - Gleason score = 8-10
  - Clinical Stage > T2b
  - Two or three Intermediate-Risk Factors
- An even more serious form of High-Risk:
  - Any Gleason grade 5 (Gleason score 9 or 10)
  - Seminal vesicle invasion
  - Pelvic lymph node metastases diagnosed at surgery

According to Lam, about 15 percent of men diagnosed with prostate cancer every year (approximately 33,000 men) fall in the high-risk category. The consensus among most experts in the United States for the treatment of Azure patients is to pursue aggressive treatment. Generally, a combination of radiation and androgen deprivation therapy (ADT) is considered better than just prostatectomy.

Imaging and staging methods for this category of prostate cancer include:

- Bone scan (to look for bone metastasis)
- CT scan or MRI of abdomen and pelvis (to look for abdominal and pelvic node metastases)
- Endorectal MRI (to look for seminal vesicle invasion)
- Na-Fluoride PET bone scan (only paid by Medicare insurance)

CONTINUED ON PAGE 9
Lam discussed “multi-pronged” treatment paths as an option for men with high-risk disease. This could involve surgery combined with radiation, ADT (androgen deprivation therapy), lymph node dissection or new drugs such as abiraterone; or may be external beam radiation coupled with ADT, brachytherapy, or chemotherapy.

For men with Gleason 8-10, surgery cure rates are low, especially when there is an abnormality on the DRE (digital rectal exam), Lam said. A few complementary measures may help improve the results of surgery, such as ADT, radiation to the prostate bed, radiation to the pelvis, and lymph node dissection.

Additionally, men with high-risk disease may improve radiation results with ADT, radiation to the pelvis, chemotherapy, or increased dosage to the prostate via seeds.

In summary, as Dr. Lam puts it, the best treatment for high-risk men is “multimodality therapy”. He breaks up the options as follows:

**Local Therapy:**
- Prostatectomy + Radiation
- Radiation + Seed Implant Boost

**Regional Therapy:**
- Pelvic radiation

**Systemic Therapy:**
- ADT for 2 years, to be started a couple months before radiation
- Chemotherapy in selected patients (investigational)

### PSA Recurrence After Surgery or Radiation

Dr. Charles “Snuffy” Myers lectured on the subject of PSA recurrence, with this take-home message: If PSA recurs after primary treatment of your prostate cancer, don’t panic. Instead, patients should take the time to understand the options and treatments available.

Most importantly, understand your PSA doubling time (PSADT). If the PSADT is >15 months, 15 years survival is common without treatment. However, if PSADT is < nine months, consider treatment; and if its < 3 months, treat it as urgent.

If PSA comes back, the tumor appears most often in the pelvic lymph nodes, and less frequently in the lower abdominal lymph nodes, bone, liver, adrenal and lung. If you had to guess, pick the iliac and obturator nodes; but it is better to use more modern imaging to find its location.

What should you do once the location of recurrence is found?

Dr. Myers states that if the doubling time is long (> 15 months), he starts with improving the patient’s general health, prescribing weight loss, exercise, a heart-healthy or Mediterranean diet. He also recommends supplementing these changes with pomegranate, vitamin D, Celebrex, Avodart, resveratrol and curcumin. This program slows progression and decreases the risk of heart disease, and thus improves the patient’s longevity and quality of life.

However, if the doubling time is faster (say < 9 months), more aggressive therapy is included with the above. He avoids salvage radiation therapy to the lower pelvis because of risk of incontinence, impaired sexual function, colorectal cancer and testicular damage. If the recurrence is located, it is treated with targeted radiation.

### Advanced Prostate Cancer

Cleveland Clinic’s Dr. Robert Dreicer led a conference session on the management of advanced prostate cancer. In his talk, Dr. Dreicer highlighted enzalutamide as the latest development for men with castration-resistant prostate cancer, that falls in the category of androgen receptor signaling inhibitor drugs. Please see Dr. Shore’s article on page 3 for a more detailed explanation of this drug.

Dreicer also discussed the immune therapy Sipuleucel-T (Provenge). He pointed out that although this treatment appears to show an improvement in patient survival, it is not a therapeutic replacement for therapy in men who need an anti-tumor response in real-time.

Lastly, Dreicer talked about skeletal issues and complications in men with advanced disease, including bone metastases and osteoporosis. Zolendronic acid (Zometa) and denosumab are two agents approved for the prevention of osteoporosis. Both have shown a decrease in skeletal-related events (SRE) in patients, and denosumab may delay progression to metastatic disease in the bone. Dreicer also discussed the use of radium-223 (alpharadin) to target bone metastases.

### Sexual Function

Dr. John Mulhall, of the Memorial Sloan-Kettering Cancer Center, discussed sexual function and side effects in men with prostate cancer.

Mulhall stressed the importance of informed consent, in which medical professionals give the patient realistic expectations before treatment about sexual recovery and function.

He cautioned that patients should not assume that the treating physician will tell them everything they need to hear – rather, many clinicians may simply tell the patient what he or she believes they need to know. Therefore, it is imperative for the patient to know what topics to bring up in advance, so that they can make a more informed decision.

When talking about realistic expectations, Mulhall said a few important conversations to have with the clinician are discussions about the prevalence of major sexual problems, chronology of recovery, and strategies to minimize and treat adverse effects.

As Mulhall bluntly put it, “the only penis-friendly prostate cancer management strategy is active surveillance”. After surgery or radiation, a number of uncomfortable side effects may occur, such as erectile dysfunction, libido loss, orgasmic dysfunction, and Peyronie’s disease, among others. Therefore, he recommends that men become well-informed of the side effects of various treatments, and talk to several doctors before choosing one.

Another important factor to consider, Mulhall said, is how important quality of life is to you as a man and as a couple. He urged patients to take their time in considering options and envisioning their sexual future.

### Miss the conference?

Each conference DVD includes recordings of all the main sessions from the 2012 conference, and is available with a donation of $150 or more. ORDER YOUR COPY TODAY BY CALLING 310-743-2116 OR MAILING US THE ATTACHED COUPON.
New Treatments

Dr. Eugene Kwon is a professor of Urology and Immunology at the Mayo Clinic. His clinic focuses on management of local/advanced prostate cancer after failure of prior treatment.

The use of the C-11 Choline PET scan has revolutionized the care of his patients. He welcomes patients in his practice, and will even help get insurance to approve the scan.

PCRI supports Dr. Kwon, and sees the value of this technology in finding the exact location of the problem causing the PSA to rise after treatment.

If an isolated metastasis is found early (the PSA needs to be 2.0 or higher), it can be treated with targeted radiation or surgery. After this treatment, if the PSA stays down, then systemic therapy may be delayed or not required.

Dr. Kwon presented numerous case studies at the conference of men who have benefited from the C-11 Choline PET Scanning followed by definitive, targeted care. We are encouraged that the FDA has approved this scan (currently available exclusively at the Mayo Clinic), and will soon facilitate more widespread availability.

For more information on Dr. Kwon’s C11 Choline presentation, you can purchase the conference DVD, or view the slides for free online at http://www.slideshare.net/PCRI_2012conf/presentations.

Sexual Intimacy

Dr. Lori Buckley spoke at the conference about intimacy in the event of impotence after prostate cancer treatment. As Buckley described, sex is not the sole means of being intimate with a partner. Rather, she breaks intimacy up into three distinct types of what she dubs "relational intimacy":

- **Affectionate touch**: pleasure, closeness, feeling desired
- **Playfulness**: pleasure, closeness
- **Communication**: closeness, feeling desired

According to Buckley, intimacy between a couple does not necessarily have to revolve around intercourse, but can also be about affectionate gestures, closeness, and feeling desirable.

Saturday Night Gala

PCRI proudly welcomed our new medical director, Dr. Dean Foster, at this year’s Saturday night gala. Dr. Foster gave a moving personal speech in which he detailed his experience with prostate cancer in both him and his father. To learn more about Dr. Foster and his vision for the Prostate Cancer Research Institute, see page 7.

Catalyst & Harry Pinchot Awards

PCRI presented this year’s Catalyst Award to two outstanding recipients, Medivation and Astellas, for their work with XTANDI in the Expanded Access Program.

Each year, the Harry Pinchot Award recognizes individuals who are making a difference in the lives of men with prostate cancer and their families. This year’s recipients were Murray Corwin and Chuck Maack.
November 15, 2012

Dear Supporter,

PCRI depends on generous charitable support to fund its mission to help patients and families.

So what is the PCRI Mission?

Perhaps that question is best illustrated with a simple example from our Helpline.

A phone call came to our Helpline from a young woman whose father was experiencing a rise in PSA four years after his prostate surgery.

We suggested her father visit the Mayo Clinic for a Choline PET scan. This new technology locates small areas of cancer that can be targeted with radiation. If radiation successfully controls the disease, her father will be spared the need for lifelong hormone therapy. The resources of the PCRI, coupled with diligent research motivated by a daughter’s love, may totally change this man’s life.

Like effective medication, information is most powerful when it reaches the right person at the right time. PCRI dispenses information like this on a daily basis through our actively growing programs:

- Our online Blue Community, which has now grown to over 2,000 members
- Our new Mentoring Program, which reaches support group leaders around the country
- Videos of this year’s excellent conference, which will be mailed all over the world
- The free quarterly Insights educational newsletter

Our dream is to continually improve the PCRI’s delivery of unbiased, medically accurate information by strengthening these programs. PCRI medical director Dr. Dean Foster and I are working hard with the PCRI wonder team to improve these programs and services for you. However, we cannot make this dream a reality without you - we need your ongoing financial support.

As we come into the year-end, please support PCRI with a tax-deductible contribution. With gratitude, we will send you the 2012 Conference DVD with a donation of $150 or more.

Your gift will make all the difference!

With warm regards,

Mark Scholz, MD
Executive Director
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 USPSTF 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.

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 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.

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 to decide between surgery and some form of radiation. It can be a complicated process, with no one telling you what to do. You will receive recommendations from doctors for the best course of treatment, but at the end of the day, the decision rests on your shoulders, and that is pretty overwhelming. This is why extensive research as well as waiting period is necessary to avoid making an overly emotional decision. This is your chance to get it right, even if you have to come up with a sexual rehabilitation plan beforehand.

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

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.

**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 advocate and educate ourselves, but we would also be open about the side effects. Terry never felt ashamed.

We 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.

**We encourage all men and couples to talk openly and honestly about the issue first, to come up with a sexual rehabilitation plan beforehand.**

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.

The truth is, sexual side effects from surgery can wreak havoc on an already unstable marriage, and be a major blow to a man’s ego. 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, and most importantly, to stay positive and never give up hope.

Cancer will steal your joy if you let it. Even after a successful treatment, anxiety about recurrence is real. I am learning to live fully present in the moment, and not worry about tomorrow. If cancer gives you anything, it is a realization that life is precious. I adore my husband. He is the hero in this story. He’s working through prostate cancer like a warrior. His positive attitude truly sets the tone for our healing process post-surgery. He’s confident with his body’s ability to heal itself, and is always willing to be open and honest about his experience.

Prostate cancer has been stressful, but we manage to love and support each other through the hardest of times, and as a result, we are stronger. With our faith in God, hope, support from family and friends, and most importantly, our love for each other, we persevere.

**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) NCCN Guidelines Version 3.2012 Prostate Cancer
SAVE THE DATE:

2013 Prostate Cancer Conference
September 6-8, 2013

We’ll see you next year!