Prostate Insights

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2015 PROSTATE CANCER CONFERENCE

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EDITORIAL

Peter Scholz,
PCRI Creative Director

Greetings Researcher! Welcome to another edition of Prostate Insights. We are excited to once again bring you new developments in the prostate cancer world.

Prostate cancer can force both men and women to come to terms with countless factors that they may not have originally considered, and questions that had not yet been asked. The more that one learns about the disease, the more one realizes how complicated the issue becomes, not just in terms of mortality, but even more commonly, with the different consequences of treatment. Often times, when treatment is unavoidable, one must move forward, dealing with the side effects as they come.

In our featured article, a team of doctors present preliminary findings from a study on managing side effects of hormone therapy with exercise, as well as some general guidelines to consider.

Our annual conference, coming up in September, is intended to be an environment where patients can be empowered through information and camaraderie, helping to diffuse the stress of the diagnosis and accompanying decisions. Our conference moderator Mark Moyad, MD and his wife Mia, share their thoughts on the importance of managing stress and provide some practical management methods.

Mark Scholz, MD, shares notable abstracts from the most recent ASCO meeting and explains how this new information is practical for patients. Lynn Farrar from Accuray explains recent studies on SBRT and compares it with other treatments. Finally, in our Helpline Corner, one of our Facilitators, Jonathan Levy, shares his own personal story with prostate cancer.

I hope that you enjoy reading this newsletter and more importantly, that you learn something new.

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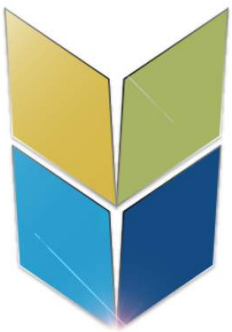

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The Benefits of Exercise During Hormone Therapy

Mitchell Gross, MD, Tanya Dorff, MD, E. Todd Schroeder, PhD, Jackie Kiwata, MS
University of Southern California

Hormone therapy, also known as androgen deprivation therapy (ADT), is a commonly used treatment for men with prostate cancer. ADT may serve as adjuvant therapy (administered after prostate removal or radiation therapy) or it may serve as primary therapy, as in the case of recurrent or metastatic prostate cancer to slow the advancement of the disease.

ADT works by reducing the body's natural production of the hormone testosterone, slowing the progression of prostate cancer cells that are dependent on testosterone for growth. While ADT improves cancer-related symptoms and survival, testosterone deprivation has numerous side effects that may have negative consequences for overall health and quality of life. Exercise has been proposed as a strategy to counter the adverse effects of ADT and is already considered to be an effective treatment for chronic diseases such as type II diabetes and cardiovascular disease. Many men treated with ADT recognize the importance of doing exercise to stay healthy; however, the exact exercise prescription may be less clear. The focus of this article will be to discuss how exercise may help with treatment-related effects, and what types of exercise may be most effective.

Body Composition and Exercise

A primary side effect of ADT is the loss of muscle and increase in body fat within 3 to 12 months of starting treatment [1]. Muscle loss reduces strength, increasing frailty, and interferes with activities of daily living. Together, the loss of muscle and gain of fat—termed sarcopenic obesity—contribute to insulin resistance and greater risk of diabetes. Numerous studies have explored how exercise might be used to counter ADT-related sarcopenic obesity and its long-term effects. Prevention of muscle loss was observed with exercise programs that were at least 3 months long and involved resistance exercise rather than aerobic exercise [2-4]. Resistance exercise utilizes weights, either machines or free weights, while aerobic exercise elevates heart rate for an extended period of time, such as walking, cycling, or swimming.

Our current work at the University of Southern California investigates how resistance exercise, either alone or combined with whey protein supplementation, can actually increase muscle mass in men receiving ADT, not just simply maintaining it [5]. Our preliminary results suggest that ideally, weight exercises should be done 3 times per week targeting major muscle groups, beginning at a moderate intensity and progressing weekly to a vigorous intensity, with limited rest periods. For example, a chest press exercise, which involves more muscle mass, is preferred over a biceps curl exercise. Furthermore, instead of the same weight for the entire program, the exercises should start at light weight and high repetitions (>12) and slowly progress throughout the weeks to heavier weight and less repetitions (~8). Finally, minimal rest (< 60 seconds) should be taken between sets as a

way of keeping the heart rate elevated in a manner similar to aerobic training.

There is less evidence for the effectiveness of exercise in reducing fat mass during ADT. In one study, men who performed aerobic exercise or who did not exercise, experienced body fat gains, while those on weights exercise did not [4]. However, other studies have shown no effect of weights exercise on fat mass [3, 6]. Since other factors, such as diet, ADT duration, and age likely influence changes in fat, more research is needed in this area to clarify the role of exercise in fat loss for men on ADT.

Physical Function

ADT-related muscle loss can lead to poorer performance on physical tasks, increasing the risk of fracture, falls, and difficulty with independent living. In one study, prostate cancer patients on ADT had reduced muscular strength and slower walking speeds compared to men of the same age who were cancer-free [7]. Many studies have found weights exercise to be beneficial in increasing muscular strength during ADT when the exercise is performed at least twice per week for 3 months [3, 4, 8]. In addition, weights exercise was found to improve functional tasks like standing up after sitting [8], although not stair climbing or balance [3].

These studies lend insight into the nature of adaptations to exercise; adaptations are specific to the movement trained. General resistance exercise using machines and weights are useful at increasing strength, but do not necessarily translate to better functional performance. In other words, to improve balance, one must do balance exercises in addition to strengthening the leg muscles. Some exercises can double as both functional and strengthening movements, such as the split squat, where one stands with one foot forward and one foot behind, and bends and straightens the legs. We use exercises such as the split squat for men on ADT to improve strength, balance, and mobility.

Fatigue

A universal side effect reported by patients on ADT is fatigue, which may be attributed to any number of ADT-related complications including loss of muscle, low red blood cells, distressed emotional state, or disruption of sleep [9]. Several studies have observed significant reductions in fatigue as a result of exercise training, be it resistance or aerobic [4, 8, 10]. In particular, performing either aerobic or resistance exercise at least twice per week reduced fatigue compared to not exercising at all.

Quality of Life

The impact of ADT on emotional state is substantial, with depressed mood and increased anxiety documented across several studies in men receiving ADT [11-13]. Long-term use of ADT and the presence of other disease was associated with poorer quality of life, while men who remained physically active had greater psychosocial well-being [13]. Indeed, many studies have demonstrated that men on ADT have a more positive outlook after participating in an exercise program compared to those who did not exercise [3, 4, 10, 14]. This greater well-being may be due to improvements in muscle strength and body composi-

tion, although the social aspect of being involved in a fitness program is also a possible factor.

Anecdotally, we have found that patients who complete our intervention have enjoyed participating in a community of exercisers and trainers as much as doing the exercises themselves. In fact, many participants finish our study on a first-name-basis with other participants whom they see every week. In addition, the exercise trainers become part of the support network for patients; through their encouragement and feedback, participants improved in their movements. This self-efficacy is often carried beyond the walls of our laboratory to work, leisure activities, or tasks of daily living. The concept of exercising with a partner is the premise behind community-based wellness classes for cancer survivors, such as the weekly class at the USC Norris Comprehensive Cancer Center. Participants are encouraged to bring a family member or friend, strengthening the bond between the patient and their partner as they exercise together.

Conclusions

More men with prostate cancer on ADT are recognizing that treatment for cancer extends beyond the doctor's office, and that exercise may be effective in managing certain aspects of the disease. A growing body of research supports the use of exercise during treatment with ADT, as exercise, particularly resistance exercise of major muscle groups, appears to lessen some ADT-related side effects. When prescribed and performed correctly, the potential benefits of exercise range from improving muscle mass and physical performance to increasing quality of life. Ideally, exercising as part of a community, either by working with a qualified trainer, taking a class with a partner, or participating in a research study with exercise, will enhance the psychosocial benefit. Men on hormone therapy interested in starting an exercise regimen should discuss with their doctor the type of exercise that would be most appropriate.

Prostate Cancer & Exercise Research

The Clinical Exercise Research Center at USC is conducting a study about improving the health in men being treated for prostate cancer. We hope to learn about how resistance exercise and protein supplementation can increase muscle mass, strength, and physical function. (USC IRB #HS–13–00315)

For more information and how you can participate, contact Jackie Kiwata, MS at kiwata@usc.edu, 323.442.2180 or visit pt.usc.edu/ProstateCancerResearch

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- **E. Todd Schroeder, PhD** is an Associate Professor and Director of the Clinical Exercise Research Center at USC.
- **Jackie Kiwata, MS** is a doctoral student under Dr. Schroeder who leads the study "Exercise and Whey Protein Supplementation for Men with Prostate Cancer on ADT," which is currently ongoing at USC.

Exercise Do's and Don'ts

Do	Don't
Perform regular exercise incorporating aerobic and resistance training 2-3x/week	**Avoid regular physical activity**
Resistance exercise should focus on large muscle groups (e.g. chest press, lat pulldown, leg press, leg curl) combined with dynamic movements (e.g. split squat, forward lunge)	**Perform only single joint exercises (e.g. using only exercise machines)**
Exercise with someone (e.g. a trainer, workout partner, or family member)	**Continue to use light weights (even as the movements become easier with training)**
Discuss starting any rigorous exercise program with your physician	

On Stress: Thoughts from Mark & Mia Moyad

Why do you go to the annual PCRI Conference? I have asked this question countless times and I have probably heard 136 fabulous different reasons. "Need more solutions for my advanced prostate cancer," "hear about the latest and greatest treatments," "compare side effects of treatment," "solutions for minor and major side effects of treatment," "what supplements to take or avoid," "how to change my diet," "want to see Moyad's beautiful face and physique" (okay I made that last one up)... Whatever your reason, there are countless individuals and couples that come up to me during and after the conference that tell me one of the most unexpected reasons they would recommend this conference is simply for stress reduction. What is Moyad talking about? Yes, the PCRI Conference is a community or a village of people coming together to share the latest thoughts and ideas on how to deal with prostate cancer. And this, my friends, provides the ultimate calming effect; not only meeting others like you but also empowering each other with more knowledge and friendships and ultimately more solutions and peace of mind. So, in honor of one of the many surprise benefits of this conference, and all the break-out sessions that can provide information and stress alleviation, I thought it would be a good time to hear from my best friend who helps people every day who are dealing with some type of stress. She has great advice on how to reduce or eliminate it. A little stress now and then is not such a bad thing, but it is the chronic stress that can be physically and mentally unhealthy and anything that we can do in order to eliminate it including reading the next column or attending the PCRI annual Conference, especially the personalized breakout sessions on Friday, Saturday, and Sunday, could change your life in an unexpected and wonderful way. However, if you still just attend the conference to see my face and Schwarzenegger-like physique (not now but when he was 25 years old) then that is okay too!

It has become almost cliché today to give the perception—realistic or not—that we are overscheduled and over-worked. When did this become our badge of honor—as if chronic stress should be revered? It appears many of us would rather be seen accomplishing a long laundry list rather than caught on a hammock, or God forbid napping. Have we convinced ourselves our busyness defines us and exemplifies our worth? What if this cycle of chronic stress is not only unhealthy but not to be admired? When was the last time you actually did lay in a hammock or found a personalized equivalent? Allow me to convince you that it is okay—permission granted—to do it differently even if it is just temporarily.

If we think about the stressors in our lives and how they can be better managed, its best if we start small, strive for a stress-free day. It is a small, realistic, and specific goal rather than a broad goal such as seeking 'less stress' in your life. We aren't aiming for a stress-free week or month, just one simple little day. We really only have the power to control this moment to the best of our ability, no more, no less, so how about aiming for enjoying this moment, this hour, and this day. Let's explore some options.

First, we have to allow ourselves permission to live a higher quality of life with less stress and anxiety. We all have stress triggers, most of us can identify several; you could probably list 10 right now off the top of your head, but how about peace prompters? Can you identify 5 to 10 ways that can cue yourself towards this peace? The idea is to identify and incorporate sensory cues that give your mind and body permission to slow down and relax.

For me, I am very deliberate about spending time in my garden. That is the first place I go in the morning and my stress-free sanctuary at the end of my day. There I experience stimulation of all 5 senses: The sweet smell of the dewy earth mixed with fresh lavender, lilacs and honeysuckle, the warm gentle breeze on my skin, the soothing songs of the birds and wind chimes, the soft silkiness of a rose petal, and even a sweet

juicy tomato in season. These all take me to a place of rest and relaxation.

Since I can't always be in my garden, I like to keep other visual cues that prompt me to feel relaxed: Calming words or quotations that speak to my heart such as art, photos of loved ones, fresh flowers, or soft lighting. All of this subconsciously helps me to manage my stress. What can serve as your own personal peace prompters?

Another opportunity for stress management is paced respiration. Deep and controlled breathing has been shown to help reduce blood pressure temporarily [1]. The mindful act of deep breathing acts as our reset button with just 3 deep cleansing breaths. I like to follow it up with an indulgent stretch as this accentuates the stress reduction intrinsically and extrinsically. Reset, permission granted.

Finally, I love to incorporate exercise into my day. The endless past and current research on endorphins, "the runner's high," and improved immune enhancement released during exercise is enough to validate this point, but you really need to experience it and live it to appreciate it [2].

Consider your intrinsic motivators, what drives you internally to achieve better health and reduced chronic stress. Think about what you're looking forward to; meeting up with an old friend, spending time with the grandkids, maybe a family reunion. Seek your inner motivation, your epiphany, and claim it. Permission granted.

When considering external motivators, do whatever it takes: buy a dog, find a friend to help encourage you, close the curtains, blast the stereo, and dance yourself to a happy place. In closing, remember that gratitude is a great way to stay connected to serenity. If we can be mindful of all of life's blessings big and small, we can help keep stress in its place. Dare to believe that you can be joyful in knowing that you can live a life of less stress regardless of your situation. Thrive despite your circumstances, your past does not define you, today does not define you, a medical report does not define you, you define you. Claim your joy. Permission granted.

Mia Moyad manages the social work department at Hope Clinic in Ypsilanti, Michigan. She received her Master's degree in Social Work (M.S.W.) from the University in Michigan with a focus in Interpersonal Health. Mia also has a private practice where she focuses on mind, body, and spirit life coaching.

Mia has facilitated several support groups including cancer support groups at University of Michigan Health System, The Wellness Center, women's support groups at Southeastern Michigan Women's Center, Packard Health. Mia is passionate about spirituality, healthy-living, family, friends and her community.

Below I've created a list of free or affordable peace prompters for you to consider, seize the day with these or create your own:

- **Go bowling**
- **Stroll the local farmers market and treat yourself to a fresh bouquet of flowers**
- **Take a dance class**
- **Create a meditation nook in your home, a soft blanket, pillow, a candle, a favorite prayer, or calming photos on the wall**
- **Revel in some bird watching**
- **Journal, release anything that's weighing heavily on your heart and mind or record your daily gratitude**
- **Write a handwritten letter to someone you love or admire, enclose a memento or photo**
- **Paint one wall in your home a calming color that says "ahhhhhh"**
- **Read a good book, or re-read an old favorite**
- **Take yourself on a date, get lost in a bookstore, go to a paper store and buy yourself a new journal or stationery, and treat yourself to an ice cream cone**
- **Attend a religious service, the *Journal of Economic Psychology* showed a direct correlation between attending religious service, and feeling more content**
- **Give a heartfelt kiss or hug to a loved one.**

references online at PCRI.org

Notable Abstracts from the 2015 ASCO Meeting

By Mark Scholz, MD, Executive Director, PCRI & Medical Director, Prostate Oncology Specialists

Every year the annual cancer meeting of the American Society of Clinical Oncology (ASCO) in Chicago, publishes the preliminary results of thousands of scientific studies. As usual, I reviewed all the scientific presentations related to prostate cancer and picked out a few that are of particular interest or applicable for men with prostate cancer. ASCO tends to publish more studies evaluating the effectiveness of treatments for men with more advanced stages of prostate cancer.

The Impact of The Government's Recommendation in 2011 to Stop PSA Screening

In **abstract #5026,** Dr. Scott Eggener from the University of Chicago provided an update on how the recommendation by the US Preventative Services Task Force in 2011 to forgo PSA screening is affecting the frequency of PSA screening in the general population. Dr. Eggener used the National Health Interview Survey to estimate the proportion of men screened for prostate cancer in 2010 and again in 2013. He found that screening significantly declined from 2010 to 2013 among all men over 50. Men ages 60-74 were most heavily tested, with a 51.2% rate of men being screened in 2010 which was reduced to 43.6% in 2013. His study concluded that "Prostate cancer screening significantly declined following the USPSTF guideline of discouraging PSA-based screening."

Does Carboplatin Improve The Anticancer Activity of Jevtana?

In **abstract #5010,** Dr. Ana Aparicio reported on 135 men with advanced hormone-resistant prostate cancer treated either with Jevtana alone or with Jevtana plus Carboplatin. PSA reductions more than 50% and more than 90% occurred in 44% and 20%, respectively, of men treated with Jevtana compared with 60% and 28% of men that received the combination. Measurable improvement of scan results occurred in 14% of men receiving Jevtana vs. 52% in men getting the combination. Side effects with Jevtana alone vs. the combination were fatigue (4% vs. 10%), anemia (2% vs. 17%), neutropenia (4% vs. 15 %) and thrombocytopenia (0% vs. 8%). The conclusion was that carboplatin improved response rates to a meaningful degree.

More Evidence for Using Statins And Metformin in High-Risk Prostate Cancer

In **abstract #5018**, Dr. Grace L. Lu-Yao evaluated 22,110 high-risk prostate cancer patients, of which 1,365 died of prostate cancer. Use of a statin medication in combination with metformin was associated with a 43% reduction in prostate cancer mortality. The benefit was present in all men but was present to a larger degree in men with obesity.

Should Men with A Rising PSA Start Hormone Therapy Immediately?

In **abstract #5007,** Dr. Nigel Spry tested the policy of starting hormone therapy immediately following PSA relapse versus waiting until further progression (metastasis, symptoms, or shortened PSA doubling time). From September 2004 to July 2012, 293 patients entered the study. After 5 years there were 30 deaths in the delayed group compared to only 16 in the men starting Lupron immediately. Lupron reduces the risk of prostate cancer death and death from other causes.

Should Men with A Rising PSA After Surgery Add Taxotere to Their Hormone Therapy?

In **abstract #5011,** Dr. Michael J. Morris evaluated relapsing patients whose PSA doubling time was less than 9 months and whose PSA was over 1.0. Half of 413 men were treated with Lupron and the other half received Lupron and Taxotere. The information is preliminary after only 2.5 years of follow-up but a statistical trend towards an improvement in cure rates was observed in the men treated with Taxotere and Lupron.

Can Men with Intermediate-Risk Get A Good Result with Seed Implants Alone?

In **abstract #e16041,** Dr. Barry Goy from Kaiser Permanente in Los Angeles evaluated the long-term treatment outcomes of seed implants compared to beam radiation in men with intermediate-risk prostate cancer. Between 2004 and 2007, 93 patients underwent iodine seed implantation while 597 patients received standard beam radiation in median dosage 7531 cGy. The projected 10 year cure rate for seed implants was 81.7%. For beam radiation it was 54.5%. Dr. Goy's conclusion from the study is that men with intermediate-risk prostate cancer can safely use radioactive seeds without adding beam radiation.

The Combination of Taxotere with Xofigo Lowers PSA

In **abstract #5012,** Drs. Michael J. Morris, Celestia S. Higano, Howard I. Scher and Charles J. Ryan evaluated 46 men, 33 were treated with Xofigo every 6 weeks in combination with Taxotere given every 3 weeks while 13 were on Taxotere only. Overall the combined treatment was well-tolerated and 30 of the 33 participants (91%) had a decline in PSA levels. This outcome contrasts sharply with the typical lack of PSA decrease observed in men treated with Xofigo alone.

Effects of Procrit on Counteracting Anemia in Men on Taxotere

In **abstract #e16064**, Dr. Ursula Steiner evaluated 139 men on Taxotere. Half of the men had 40,000 units weekly Procrit added to their chemotherapy regimen if their hemoglobin level dropped below 10.5. When their hemoglobin rose above 13.0, the Procrit treatment was held. Only 9.1% of the men on Procrit developed a hemoglobin less than 10 whereas 24.6% of the men without receiving Procrit had hemoglobin levels under 10. The men on Procrit required significantly fewer blood transfusions ($p = 0.026$). The overall survival rate was significantly higher (62.5% vs 29.3%, $p < 0.001$) in the men treated with Procrit.

Conclusion

You can see that with all the new agents for treating prostate cancer becoming available, many of the studies are starting to address the optimal way to sequence and combine different therapies. Also, ever since the CHAARTED study came out last year documenting a 17-month survival advantage of starting Taxotere immediately at the time of diagnosis, greater attention is being paid to the importance of studying the potential benefit of using effective agents early after diagnosis. I expect this policy of combining anticancer therapies and using them early will continue to gain adherents.

An Introduction to Stereotactic Body Radiation

Lynn Farrar, CyberKnife Patient Access

Optimal treatment for any specific individual with prostate cancer is based on a long list of important considerations including his specific risk category (low, intermediate, or high), his age, health, baseline erectile function, his baseline urinary function, prostate size, and last but not least, the raw skill of the proposed treating physician. This short article is a brief report on a body of data collected on almost 2,000 patients treated with Stereotactic Body Radiation Therapy (SBRT) for prostate cancer. This report was recently published in the January 22, 2015 issue of* Frontiers of Oncology. *The full article can be viewed at http://journal.frontiersin.org/article/10.3389/fonc.2014.00369/abstract

This study enrolled patients in a Registry for Prostate Cancer Research (RPCR), with this particular data set representing patients at 45 CyberKnife centers, including academic centers, hospital-based practices, and free-standing centers. This registry was developed to collect data on the outcomes of prostate SBRT in a variety of real-world clinical settings.

What Is SBRT?

SBRT accurately delivers very high doses of external radiation beams to the whole prostate gland, thereby treating the prostate tumor within, while minimizing extra-prostatic radiation exposure to the adjacent normal tissues.

Because SBRT delivers a much higher dose of radiation during each visit to the facility, the overall treatment time is sharply reduced. Generally a full course of therapy can be completed in four to five sessions over the course of one to two weeks. Other external radiation treatments for prostate cancer often require approximately 35 to 45 sessions of radiation therapy over six to nine weeks. CyberKnife is one of several SBRT systems available but it is the only system that is entirely robotic.

Rpcr-Reported Treatment Effectiveness

In this particular registry report from the RPCR, the rate of PSA relapse-free survival was 92 percent in the entire cohort of patients at two years. This outcome is similar to other published outcomes for the CyberKnife system, including outcomes on 1,100 patients published in 2013 in the journal *Radiotherapy and Oncology*.

In fact, several other papers have been published with median follow-up of five to seven years. To date, CyberKnife has been the subject of approximately two dozen peer-reviewed clinical papers, more than any other type of SBRT technology.

Side Effects

The survey published in *Frontiers of Oncology* also reported on side effects related to bowel, bladder, and sexual functioning. During the first three months, the most commonly reported side effects involved urinary symptoms of urgency, frequency, and/or dysuria (pain during urination). 10% of patients reported urinary symptoms persisting more than three months after treatment. Urinary quality of life score remained unchanged before and after treatment. The incidence of persistent bowel complaints was low.

The rate of erectile dysfunction was similar to what has been observed with other forms of radiation therapy (IMRT, seed implants, and proton therapy). Approximately 80% of men younger than age 70 maintained erections sufficient for intercourse following SBRT; 55% of men older than age 70 were able to maintain potency. This analysis does not adjust for the normal 2-3% increase an-

nually in erectile dysfunction that occurs from other health conditions as men get older.

Cyberknife Compared to Other Types of SBRT

The prostate gland can move unpredictably throughout the course of treatment, making the ability to track, detect, and correct for motion during treatment critically important. In fact, the prostate has been documented to move as much as 5 millimeters in less than 30 seconds because of normal patient bodily functions such as filling of the bladder, gas in the bowel, or even slight patient movement during the procedure.

Unlike any other radiation treatment, the CyberKnife system continually tracks and automatically corrects the radiation beam to adjust for movement of the prostate in real-time throughout the entire treatment session. This capability enhances the doctor's ability to accurately deliver high doses of radiation to the intended target while still preserving the surrounding healthy tissue to minimize potential side effects.

Paying for SBRT

SBRT for low and intermediate-risk prostate cancer is covered by Medicare in all 50 states and the District of Columbia. In addition, most private insurance payers and health exchange insurers cover SBRT treatment for prostate cancer. It is always best to check your insurance policy, and if applicable, be sure to review your employee contract to determine if your insurance coverage benefits are limited.

For more information on SBRT, check with a radiation oncologist. For contact information for centers specifically offering the CyberKnife System for prostate cancer, visit http://www.cyberknife.com/

helpline corner: My Story So Far

By Jonathan Levy, PCRI Educational Facilitator

In February 2006, with a PSA of 4.0 ng/mL, my urologist decided that I should have a prostate biopsy. The result? The pathologist found no cancer. Since the biopsy results were benign, the doctor reassured me that I was "just one of those men, whose PSA of 4.0 ng/mL, was normal." Because of this, I wasn't re-tested for the next three years.

In 2009, during a routine physical, and because it was now long overdue, I decided that it was time to take a PSA again. It came back at a whopping 32 ng/mL. Of course, this triggered a repeat biopsy, and this time I was diagnosed with prostate cancer. My Gleason score was 3+4=7; stage T2b. A CAT and bone scan were ordered to rule out any metastatic disease.

My wife, Doris, and I went to a meeting with the urologist to review the results, and to discuss my treatment options. When we arrived at his office, his demeanor made it clear to both of us that things weren't going to go as planned. The CT scan showed that, "the cancer had already metastasized to your liver," he said. He explained that the only treatment available now was hormone therapy, using a drug called Lupron, and, that it would only be palliative, since a cure was now impossible.

My wife and I left the meeting in total disbelief and shock. We felt helpless, confused, and numb. "How do we break this news to our children?", we asked ourselves; our lives had been shattered. The next several days were an emotional roller coaster, filled with ups and downs, sleepless nights, and confusion. But, what eventually came out of the chaos was a slowly but surely formed conviction that there was something fundamentally wrong with this whole sequence of events; it didn't add up.

I started researching on the internet and found that a liver biopsy could be done, to confirm whether the doctor's

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Jonathan Levy (right) is a retired motion picture film editor, prostate cancer patient, and an educational facilitator for the PCRI Helpline.

diagnosis of liver metastases was correct, or not. So, I requested that one be done immediately. The radiologist felt that the location would be too dangerous to biopsy, so another CAT scan was ordered instead. The results showed that what had been assumed to be cancerous liver lesions by my urologist, were actually benign hemangiomas.

To top it all off, the urologist reacted to the news as if nothing out of the ordinary had happened, and without skipping a beat, brought up the option of radiation therapy. Later, when I finally did get to see the original CT report, I was stunned. In it, the radiologist had clearly suggested to the urologist that a repeat scan be done with a hemangioma protocol.

I know that this is an extreme example, and I realize, that in his own way, he was probably only doing what he thought was best for me, but put yourself in my place. If this had just happened to you, would you continue treatment with this doctor?

What would you call this? Misdiagnosis? Diagnosis error? What I do know now, is that liver metastases, being so dangerous, are less likely to respond to hormone treatment. So, "why", I ask myself, "did he offer me this treatment option?"

This whole sequence of events drove the point home to me, and made it clear what needed to be done. No, I did not hire a lawyer. I had just turned a corner, and, I now had to become my own healthcare advocate.

So, I found another doctor. This time I asked the questions and offered the input that would help achieve what I wanted to accomplish in my own treatment. These were the questions that are repeated many times over with the men and women I speak with on the PCRI Helpline: Is my diagnosis correct? Should the pathology be reviewed? Are there tests that need to be done to provide additional details, including newer tests for genetic markers?

In my case, I chose radiation treatments along with adjuvant hormone therapy. My PSA responded so well that it reached a nadir of 0.1 ng/mL. For the next couple of years, it remained stable.

But, in 2013 my PSA started to rise, slowly at first, incrementally, and then, much more significantly. When it hit 10 ng/mL, and after doing a lot of research, I decided that I would try to find the source of the recurrence.

My journey now took my wife and I all over the country. First, we tried an MRI-fusion targeted biopsy. It came back negative. Next, we traveled to Minnesota for a C-11 Choline PET scan. Negative. I underwent the misery of a thirty-core transperineal mapping biopsy. Also, negative. And, finally, I had an F-18 Sodium Fluoride PET scan. It, too, came back negative. Like so many men with recurrence, I just wanted to know where it was.

In April 2014, and with a PSA that had risen to 34 ng/mL, I requested that we retest with an F-18 Sodium Fluoride PET bone scan. Previously, my PSA was 10 ng/mL, and in my case, too low for even the highly sensitive F-18. But this time around, the scan clearly detected bone metastases in brilliant illumination. It was quite a light show. The upside of this new diagnosis was that I was now able to qualify for a clinical trial that I had long been hoping to enroll in.

In July 2014, I started on the SWOG 1216 Trial, a trial using the experimental drug *TAK-700*, with Lupron, in men with newly diagnosed metastatic disease, who are hormone sensitive. I believe that participating in a trial brings with it two definite benefits: one, you get to try an experimental drug, not otherwise available, that may offer as of yet unknown clinical benefits. Two, you are loaning the prostate cancer community your body and its disease in the hopes that others will derive a future benefit.

After being on the trial for six months, at my request, we re-scanned with another F-18 Sodium Fluoride PET scan. This time, the results were astounding: "No new suspicious hypermetabolic osseous foci are identified. No suspicious increased focal activity to suggest active osseous metastases. The majority of the previous noted osseous metastases are now more sclerotic and are without significant activity."

This has been a long and winding journey. Men know instinctively that a prostate cancer diagnosis will change their lives forever. It certainly has for me.

As a patient advocate for the Prostate Cancer Research Institute Helpline, it is my job to listen, as men try to find a way to express what they are going through. The masculine ideal is to suffer in silence, and many do. We say otherwise: we do our best to impart from our own experiences, what we have learned from our personal journeys. We use evidence-based information to help men empower themselves. We support them, their wives, and their families as they journey their way toward the goal of patient-centered care.

Call the PCRI Helpline at 800.641.7274

2015 PROSTATE CANCER CONFERENCE

Travel

The conference is held at the Los Angeles Airport Marriott. A special room rate of $105/night is available until August 20th 2015 by calling the Marriott directly at 310.641.5700 or by visiting www.PCRI.org for the online booking link.

Discounted airplane booking with DELTA is available via www.delta.com. When booking online, select *Book A Trip,* click on *Advanced Search* and use the **meeting code NMKZ8.** Discount car rental through AVIS using discount code **#D374541.** There is a complimentary shuttle from LAX terminals to the Marriott. A reduced self-parking rate of $12/day is available for those who are driving to the conference.

JOIN PATIENTS & CAREGIVERS, LEARN ABOUT THE **LATEST PROSTATE CANCER DEVELOPMENTS** FROM RENOWNED MEDICAL EXPERTS

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Johnson & Johnson
Dendreon — Targeting Cancer, Transforming Lives®
Takeda MILLENNIUM THE TAKEDA ONCOLOGY COMPANY
BAYER
astellas
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MEDIVATION — Driven by science. Focused on life.
SANOFI
AMGEN Oncology

Overview

The Prostate Cancer Research Institute's annual conference is the leading conference for prostate cancer education and support. The conference provides a weekend of educational sessions on treatment options, both new and of landmark importance, and addresses lifestyle and quality of life issues. Information is presented by world-renowned physicians and researchers. The keynote sessions are moderated by Dr. Mark Moyad, a leader in the fight against prostate cancer, who makes it personal and relevant to the patients in the audience. In addition, there are opportunities throughout the 3-day event to participate in Q&A sessions with the faculty, hear in-depth presentations about particular treatment options, attend support groups with other patients, and meet with various organizations and companies who provide services and products for prostate cancer patients.

Moderators

Mark Moyad, MD
Jenkins/Pokempner Director of Complementary & Alternative Medicine
University of Michigan Medical Center

Mark Scholz, MD
Medical Director
Prostate Oncology Specialists &
Executive Director
Prostate Cancer Research Institute

*Speakers & Topics

Tomasz Beer, MD
Oregon Health and Science University
Zytiga and Xtandi

Matthew Cooperberg, MD
University of California San Francisco
Active Surveillance

Charles Drake, MD
Johns Hopkins School of Medicine
Immune Therapy

Peter Grimm, DO
Prostate Cancer Center of Seattle
Seed Implant Radiation

Daniel Margolis, MD
University of California Los Angeles
Prostate MRI

John Mulhall, MD
Memorial Sloan-Kettering
Sexual Side Effects

William Oh, MD
Mount Sinai School of Medicine
Hormone Resistance

**subject to change*


Helpline Panel


Speaker Q&A


Support Groups


Exhibit Hall


Special Guests

FEATURING:

- **PRESENTATIONS FROM WORLD RENOWNED PHYSICIANS**
- **INFORMATION ON NEW RESEARCH, DRUGS, AND CLINICAL TRIALS**
- **LECTURES ON EVERY STAGE OF PROSTATE CANCER**
- **SESSIONS ON REDUCING SIDE EFFECTS AND MAXIMIZING QUALITY OF LIFE**
- **SUPPORT GROUP SESSIONS**
- **INFORMATION SESSIONS WITH PCRI'S HELPLINE STAFF**
- **EXHIBITS FEATURING ORGANIZATIONS & COMPANIES LEADING THE FIGHT AGAINST PROSTATE CANCER**
- **EXPLORE LOS ANGELES BY SIGNING UP FOR OUR EXCURSIONS**

- **Roundtable discussion:** A panel where conference faculty discuss their medical opinions on real clinical cases.
- **Q&A with the Speakers:** Conference attendees ask faculty specific questions in a more intimate setting.
- **Ask the Experts:** 90-minute interactive sessions that focus on topics such as medical oncology, urology, radiation oncology, immunotherapy, nutrition, a prostate-friendly lifestyle and much more.
- **Support Groups:** With the help of PCRI's partners and professional facilitators, support group meetings are available to patients and their significant others.
- **Exhibit Hall:** Ballroom where attendees view display booths and materials, interacting with representatives from exhibiting companies and partnering organizations.

PROSTATE CANCER RESEARCH INSTITUTE

Helping Men Research Their Options

Register today at:

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2015 PROSTATE CANCER CONFERENCE

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