



# PCRI Insights

New Developments in Prostate Cancer Treatment      Patient & Physician in Co-Partnership

November 2013 VOL 16: NO 4

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# Report from the Annual Meeting of Radiation Therapists

By: Mark Scholz, M.D.



Dr. Mark Scholz

Last September, thousands of radiation therapists attended ASTRO, the annual radiation therapy conference. Thousands of scientific studies were presented. Several hundred were on the topic of prostate cancer. After sifting through every abstract about prostate cancer, I judged six to be important enough for comment in this month's issue of Insights: Three are about radiation, two about hormones and one about PSA doubling time.

One of the most compelling scientific reports came from a well-known center of excellence. They used state-of-the-art radiation techniques, and studied a large number of patients. In **abstract #311**, Dr. Zelefsky from Memorial Sloan Kettering reported the cure rates with very high dose IMRT (86 Gy) compared to the cure rates achieved with IMRT *combined* with a seed implant boost. The study group consisted of 870 men with *Intermediate-Risk* prostate cancer (TEAL). Fifty percent of the group treated with IMRT alone got hormones while only 30% of the IMRT plus seeds group got hormones. The cure rate at seven years was 81% in the men treated with high-dose IMRT and 92% in the men treated with IMRT plus a seed implant boost. There was no difference in late term side effects.

**Comment:** This is an important report. Despite using the finest, most state-of-the-art IMRT, cure rates for men with *Intermediate-Risk* prostate cancer treated with IMRT alone were clearly inferior to what can be achieved when IMRT is coupled to a seed implant boost.

Another study addresses one of the biggest issues men with newly-diagnosed prostate cancer face, especially younger men—losing sexual potency. However, there are relatively few reports describing the frequency and severity of this problem. In **abstract #2497** Dr. Shasha from Beth Israel Medical Center in New York reported the incidence of sexual function being preserved in 68 healthy, nonsmoking, sexually potent men under the age of 60 (median age 56) who were treated with radiation. Prior to radiation none of the men were using Viagra, Cialis or Levitra. Three years after radiation 90% of the men remained potent. Only 10% required medication. An additional 10% use medication for potency enhancement.

**Comment:** According to this study, the rate of potency preservation in young men treated with radiation is clearly superior to what can be achieved with surgery.

The next study addressed the issue of doing radiation after surgery if the surgical margin is positive. A positive margin (tumor left behind) occurs between in 10% to 50% of the time after surgery. Postoperative radiation can reduce the incidence of future PSA relapse. However, studies have shown that about half of the men who have positive margins will remain cured with no radiation at all. Therefore, some experts have argued that radiation should only be administered to men if their PSA begins to rise, thus sparing half of the men from the potential side effects of radiation. The real question that needs to be answer is, "Will the men who delay radiation until the time of PSA relapse experience a higher rate of subsequent metastases?"

In **abstract #261** Dr. Nguyen from Dana-Farber Cancer Institute looked at the combined results of the three largest randomized prospective studies in combination. Over 1700 patients were evaluated. Dr. Nguyen found that there was a 13% higher incidence of metastasis in the men treated at the time of PSA

relapse compared to the men who were treated right after surgery. However, because the 13% difference is relatively small, statisticians point out that there is a chance that this small difference is only the result of statistical variation.

**Comment:** In these studies the group of men treated after a PSA rise didn't get radiation until their lapse PSA was above 1 or 2! We know from other studies that the cure rate would have been much better if the radiation was started before the PSA rose above 0.5. Despite this, the metastases rate of the men who got delayed radiation was only 13% lower than the men who were treated right after surgery when their PSA was still undetectable. These studies strongly suggest that men with positive margins can consider waiting and monitoring closely. Radiation can be started at the first sign of a PSA relapse without facing a greater risk of future metastases.

The number one study of the whole conference addressed a perennial question that has been hanging in the air for years: How long do you continue hormones in men with *Intermediate-Risk* disease (TEAL) who are being treated with radiation?

Dr. Pisansky from the Mayo Clinic headed up a prospective randomized study of over 1500 men with Intermediate-Risk prostate cancer treated with radiation plus 4 months of hormone blockade (arm A) compared to radiation plus 8 months of hormone blockade (Arm B). Prostate cancer mortality after 10 years was 5% in Arm A compared to 4% in Arm B, a difference so small it could easily be due to statistical variation. Relapse rate was 24% in Arm A compared to 23% in Arm B.

**Comment:** The results of this study, along with the results of previous studies using even longer duration hormone therapy clearly show that maximum benefit from hormones is achieved by 4 months. Another study addresses the following important question: Should you give hormone therapy at the same time as radiation in men with relapsing disease after surgery (INDIGO).

In **abstract #1024** Dr. Jackson from the University of Michigan reported on 680 men who had radiation after surgery along with variable amounts of hormone therapy. More than half received no hormone therapy at all. They found that mortality was 50% lower in men who were administered hormone therapy for 6 months. Mortality was 90% lower if the hormone therapy was continued for 2 years.

**Comment:** Relapsing prostate cancer after surgery is potentially aggressive. Logic would dictate that longer duration treatment with more effective hormone therapy should improve survival. This study strongly supports using longer-term hormone blockade in men being treated with radiation for relapsed disease.

The last study looked at the rate of PSA rise (PSA doubling time) after treatment and its effect on long-term survival. Previous reports have already determined that PSA doubling time is an important indicator of survival that is second only to the predictive power of PSA *nadir* after hormone therapy. **Abstract #1016** reported on the survival rates of men at Memorial Sloan-Kettering Cancer Center who were originally treated with IMRT.

Dr. Zelefsky evaluated the survival rates of 419 men who were relapsing. He and his collaborators looked at prostate cancer specific survival rates depending on whether the PSA doubling time was above or below 6 months. The seven year mortality rate for men with PSA doubling less than 6 months was 40% with a median time to mortality of 8 years. In the men whose doubling time was above 6 months, there was only a 10% risk of mortality and in those 10%, mortality occurred after a median of 16 years.

**Comment:** The outcome of men with relapsed disease (INDIGO) can vary greatly depending on the response to hormone therapy (PSA nadir) and the rate of PSA rise (PSA doubling time). This study well-illustrates the important differences between the various diseases we term "prostate cancer." □



# Payment Assistance for Under Insured Patients

## Patient Access Network Foundation

By: Emily Acland

The Patient Access Network (PAN) Foundation offers financial assistance to patients who lack full insurance coverage, allowing access to treatments that were previously out of reach. Founded in 2004, PAN is an independent non-profit organization dedicated to providing financial assistance to underinsured patients. The PAN Foundation has provided more than 200,000 grants and contributed more than \$350 million in much-needed financial assistance.

In 2012, PAN started a major push to raise funds to give castrate-resistant patients access to necessary treatment. When first opened, the Foundation's Castrate Resistant Prostate Cancer (CRPC) program enrolled more than 600 patients in 5 weeks, demonstrating a demand far beyond our expectations and fundraising capacities. As of September, 2013, nearly 2,500 men have enrolled in the CRPC program alone. As such we allocated more than \$22 million in financial assistance for specialty medications. The availability of funds depends solely upon gifts from donors – both individual, and corporate. Available funds are our mission and goal, but can never be guaranteed. PAN now has 4 distinct co-pay assistance programs and one, first-of-its-kind, travel assistance program.

### Current Co-Pay Programs Include:

- Androgen Receptor Inhibitor Treatments for Advanced Prostate Cancer
- Immunotherapy Treatments for Genitourinary Cancers
- Metastatic Castrate Resistant Prostate Cancer (covering all treatment types) – now in partnership with ZERO - The End of Prostate Cancer
- Radioisotope Treatments for Castrate Resistant Prostate Cancer

For specifics about which treatments fall into which category, call PAN at 866-316-PANF (7263).

### Applying for PAN Assistance:

- Patients or Caregivers: Apply online at [www.PANfoundation.org](http://www.PANfoundation.org) or call 866-316-PANF (7263).
- Health Care Provider or Office Representative: Apply online at [www.PANfoundation.org](http://www.PANfoundation.org) or call 866-316-PANF (7263) or visit PAN's online Provider Portal to easily manage multiple patient grants within your office by visiting [providerportal.panfoundation.org](http://providerportal.panfoundation.org).
- Specialty Pharmacy: Register and apply on patients' behalf by visiting [pharmacyportal.panfoundation.org](http://pharmacyportal.panfoundation.org).

### Who Can Receive PAN Assistance, And How Much Assistance Will They Get?

In order to best suit the needs of specific patient populations, PAN assistance varies by program. All programs abide by the following eligibility guidelines:

- Patient must be diagnosed with the disease which is covered by the program for which they are applying.
- Patient must have insurance that covers the medication for which they are seeking assistance. Note: For the program titled "Metastatic Castrate Resistant Prostate Cancer", patients must have Medicare insurance.

- Patient must reside and receive treatment in the United States.
- Patient's household income must fall at or below a certain percentage of the Federal Poverty Level.

**Note:** For all advanced prostate cancer programs, this percentage is 500% (below \$77,550 for a family of two).

PAN grants are awarded on a 12-month basis, but also include a 90-day "look back" period which allows patients to be reimbursed for costs incurred up to 3 months prior to enrollment in PAN assistance. In some cases, patients may apply for a second grant during the same 12-month eligibility cycle if their initial grant amount was not sufficient in covering their out-of-pocket medication costs.

Initial grant amounts for advanced prostate cancer patients are as follows:

- Androgen Receptor Inhibitor Treatments for Advanced Prostate Cancer - \$7,500
- Immunotherapy Treatments for Genitourinary Cancers - \$10,000
- Metastatic Castrate Resistant Prostate Cancer – now in partnership with ZERO - the End of Prostate Cancer - \$7,500
- Radioisotope Treatments for Castrate Resistant Prostate Cancer - \$10,000

Additional program information can be found on [www.PANfoundation.org](http://www.PANfoundation.org).

### PAN Travel Assistance Services:

PAN offers travel assistance for patients seeking treatment for Metastatic Castrate Resistant Prostate Cancer. Our Travel Assistance Program covers approved transportation, lodging, and ancillary travel expenses. Patients do not need to be insured to qualify for travel assistance and can receive up to \$2,500 per year through the program. Patients can even enroll in PAN's Travel Assistance Program while enrolled in a co-pay assistance program, however participation in a co-pay assistance program is not required. To apply, call 866-316-PANF (7263) and select option 6.

*PAN runs solely on the generosity of our donors, who make it possible for us to change the lives of so many patients. We are grateful to the foundations, corporations, and individuals who help make it possible for patients to afford the potentially life-saving medications they otherwise would have gone without. To become a source of help and hope for patients in need, visit [www.panfoundation.org/ways-to-give](http://www.panfoundation.org/ways-to-give). □*



Patient Access Network  
f o u n d a t i o n



# Thanks for making this year's conference a success!



## So Many New Things in 2013 PCRI Conference

By: Mark Scholz, M.D.

Every September, the PCRI invites leading prostate cancer experts to share their thoughts about the latest developments in prostate cancer treatment. The pace of scientific discovery in this field accelerates more rapidly each year. For past conferences, we often had to search high and low for sufficiently interesting clinical studies to fill the two-day agenda of the conference. However, in 2013 our struggle was to find sufficient time in our limited schedule to introduce all of these new developments. Hopefully this brief summary can bring home some of the more important highlights.



Prostate cancer treatment needs to be personalized for each patient, a theme which constantly surfaced throughout the weekend. For a couple years now, PCRI with its *Shades of Blue* program has focused on emphasizing the importance of each individual knowing the characteristics of his specific disease. However, knowing one's Shade is only the beginning. New genetic tests can enable an even more specific understanding of the subtle differences between disease behavior within the same shade category.

For example, during the interlude between Dr. Bahn's two live prostate biopsy patients I was able to briefly introduce two new genetic tests that are now commercially available, **Prolaris** and **OncoType Dx**, tests that can help men in the Sky and Teal shades obtain a more accurate measure of the aggressiveness of their tumor. Both tests look at multiple genes in the prostate cancer cells that are removed at the time of prostate biopsy. Prolaris predicts the risk of ten-year mortality from prostate cancer. OncoType can refute or confirm the accuracy of the initial risk category of the *Shade of Blue*.

Two additional genetic tests need to be mentioned. **Confirm MDx**, another test that can be performed on a previously performed needle biopsy, can "sniff out" the presence of prostate cancer *even if the needle biopsy was read as clear*. This test can provide additional assurance that a negative biopsy is truly negative and that the needle did not simply miss the cancer. Confirm MDx is about as accurate as doing a second biopsy but, thankfully, it eliminates the need to go back to the doctor for more snips.

The **Know Error** test is also a genetic evaluation that can confirm a genetic match between the prostate tissue removed during a biopsy and an additional swab of cells obtained from the inner lining of the patient's mouth. This test helps prevent mistakes in a patient's identity by inadvertent switching of specimens in the lab. Studies have shown that errors such as these occur in about 1% of the patients in the United States.

The stark contrast of personalized medicine with public health medicine was vividly conveyed in the debate about PSA screening between **Mack Roach**, M.D., a radiation oncologist from UCSF and **Timothy Wilt**, M.D., a public health expert from the University of Minnesota. Dr. Wilt cogently argued that in the sense of the global population, PSA screening does more harm than good because it causes unnecessary radical treatment to be given to 80,000 men each year. Dr. Roach countered that forgoing PSA screening would increase prostate mortality from 30,000 men a year to 50,000 a year by failing to diagnose and treat the men who have more serious types of prostate cancer.



# Our Programs Need Your Support

## ◆ Prostate Cancer Conference

*Making A Positive Impact on Quality of Life*

## ◆ PCRI Helpline

*Empowering Patients And Their Advocates*

## ◆ PCRI Website

*www.pcri.org Providing Easy Access to Empowering Information*



## ◆ Blue Community

*Family Network And Sharing Forum*

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*Keeping You Informed And Updated*

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### 2013 Conference DVDs

will be available for a donation of \$150 or more.

### 2012 Conference DVDs

available for a donation of \$100 or more.

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## ◆ Prostate Cancer Research

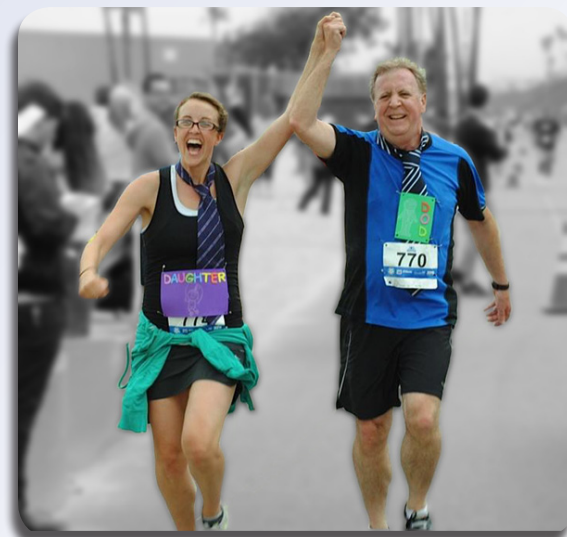
*Breakthrough Discoveries*

## ◆ Cancer Awareness

*Keeping Prostate Cancer A Priority*

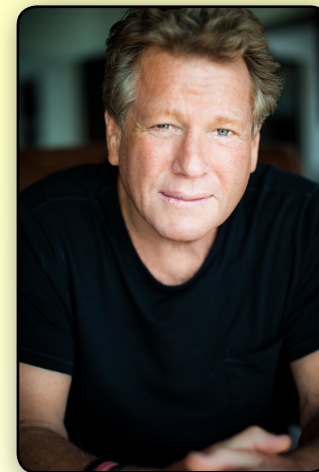
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Your donations keep these programs alive.

## RYAN O'NEAL



### I HATE CANCER

Last year I faced a real scare when the doctor felt a prostate abnormality during my annual physical. His concern that it was possibly prostate cancer turned out to be true. It was a Gleason 4 + 3 = 7, the kind that needs treatment. I was referred to a world-class doctor and thankfully, I'm in remission without any lasting bad effects.

Prostate cancer is actually the second cancer bullet I have dodged. Ten years ago I was diagnosed with chronic myelogenous leukemia. Back then a visionary doctor had the courage to start me on a new investigational medication. It worked.

But in 2006 my precious Farrah was diagnosed. We battled against the cancer for three years, traveling the world looking for an answer. To raise awareness, and to help others with cancer, "Farrah's Story" was aired as a two-hour documentary on NBC, five weeks before she passed. Our son Redmond and I were so fortunate to have had Farrah in our lives and still grieve our great loss.

I know that I am not alone and that many of you have been through similar struggles and heartaches. Most of you receiving this letter have experienced the intense stress of a cancer diagnosis. You have shared in the fear and frustration that comes with searching for trustworthy resources in a minefield of misinformation.

The Prostate Cancer Research Institute is a charitable foundation created specifically to provide unbiased guidance by helping men know all their options. Their *Helpline* provides personalized one-on-one conversation and their *website* makes information available to over a million visitors a year.

As the end of the year draws near, let's lavishly support the PCRI's mission. Your generous donation will help us bring assistance and clarity to thousands of men.

Sincerely,

Ryan O'Neal



**P.S. DVD's for the 2013 conference will be available soon!**



The debate was of particular interest, because these doctors come from two totally different perspectives, the world of public health and the world of personalized medicine. PSA screening is a double edged sword that is proven to result in harm when ignorant patients and doctors let their cancer fears drive them into unnecessary radical treatment. But PSA is not exactly the cause of overtreatment. Overtreatment is caused by a lack of education about the truly benign nature of *Low-Risk* disease. Forgoing PSA screening altogether is also a dangerous policy as it would lead to delayed diagnosis of *High-Risk* prostate cancer to a point when it is no longer curable.

"Prostate cancer treatment needs to be personalized for each patient..."

-Dr. Mark Scholz

**Nick Vogelzang, M.D.** was charged with the impossible task of reviewing all the new therapies for men in the *Royal Shade of Blue* (advanced prostate cancer). The list has now expanded to include **Provenge, Zytiga, Xtandi, Jevtana** and **Xofigo**. Xofigo is a brand new form of targeted, highly-potent radiation treatment that was FDA approved this summer that is administered monthly by intravenous injection. Xofigo is attracted like a magnet to the malignant areas in the bone where it concentrates and delivers high potency radiation.

One of the most amazing presentations of the whole conference was given Saturday evening by Dr. **David Hung** the CEO of Medivation at our gala dinner. Dr. Hung shared an incredibly inspiring personal story about coming out of retirement ten years ago to start the company that developed **Xtandi**, the new, recently FDA-approved pill for advanced prostate cancer. Bringing a brand new treatment to market in less than ten years is close to miraculous. In addition to Xtandi's potential in advanced disease, it also has potential for men with early-stage prostate cancer, a topic I blogged about in more detail in September.

Awareness about new ways to reduce treatment-related side effects got a huge boost when Dr. **Duke Bahn** introduced his celebrity patient **Ryan O'Neal** who is a **Focal Cryosurgery** success story. I must confess, despite the wonderful potential of focal treatment, the real highlight of the presentation was Dr. **Mark Moyad's** interview of Mr. O'Neal and all the information he elicited about Farrah Fawcett, Lee Majors and the Hollywood entertainment world. Mr. O'Neal showed he is a real trooper, coming to the conference even though he was suffering from the flu. He has been very grateful for the absence of debilitating side effects from his treatment and wanted to volunteer his time to raise awareness.

To me, perhaps the most encouraging talk about what we can expect in the near future was given by Dr. **Chuck Drake** from Johns Hopkins who discussed recent developments in the area of harnessing the anti-cancer powers of the **immune system**. Dr. Drake shared about the amazing results seen in the treatment of metastatic melanoma by the simultaneous use of two immune treatments. Durable complete remissions are being seen in a stubborn disease that in the past has been considered totally hopeless. Dr. Drake is the preeminent clinical expert in the world on immune therapy for prostate cancer and is doing groundbreaking research on immune therapy for prostate cancer. We were most privileged to have him come to the conference and share his expertise.

Space is too limited to cover all the excellent presentations. Stay tuned for the conference DVD's which will be available shortly. Also, please come and visit us at our new, recently updated PCRI website. Join the PCRI's Blue Community to learn more about prostate cancer and to help others better understand this complex world. □

# Live On-Stage Prostate Biopsy at The PCRI Conference

Duke K. Bahn, M.D.

Director, Prostate Institute of America, Ventura, CA

This is a follow-up report to the live prostate ultrasound and biopsy demonstration that was performed at the PCRI conference on September 7, 2013.



You never know what might happen at our September PCRI conference. This year Dr. Duke Bahn somehow convinced two volunteers to undergo a live targeted biopsy on stage at the conference. The procedure was videoed from an adjoining room complete with sound effects and was shown in its full glory to the conference attendees. The amplified snap of the biopsy gun sent shivers up the spine of the audience in the auditorium.

Both patients were considered potential active surveillance candidates per random 12-core biopsies that had been done by an outside urologist. However, suspicious findings detected by Color Doppler Ultrasound indicated the possible presence of occult, higher-grade disease that had been missed by the random biopsy.

The live images from the Color Doppler used by Dr. Bahn were projected onto a large screen during the presentation. After Dr. Bahn identified the suspicious area in the prostate he fired his needle gun, leaving a "vapor" trail across the gland that was easily seen on the video feed.

At the conclusion of the presentation, Dr. Bahn promised to report his pathologic findings in the next issue of Insights. The pathologic findings of the biopsy are listed below:

## Patient #1 Findings:

- 1. Gleason 7=3+4 with up to 64% of the tissue cores showing cancer (vs. 30% by the initial biopsy).
- 2. Left neurovascular bundle was positive and showing invasion from the cancer.

**Conclusion:** After targeted biopsy, the cancer is no longer found to be a Low-Risk disease. It is Intermediate to High-Risk. Due to these findings, he will no longer be a candidate for active surveillance. If he had not undergone this targeted biopsy he would have inappropriately been continued on active surveillance with disease that extends outside the prostate into the surrounding neurovascular bundle. The test provided a clearer picture of this man's disease allowing for the choice of a more appropriate treatment strategy.

## Patient #2 Findings:

- 1. Gleason grade 6 cancer with a 20% tissue core invasion, a larger cancer than was detected by the random biopsy. Therefore the lesion detected by Color Doppler is indeed the "index tumor".

**Conclusion:** The gentleman's cancer is confirmed to be Low-Risk. He can consider active surveillance to manage his cancer. He will need a PSA test every three months and an ultrasound in another 6 months. By doing so, we can clearly view the PSA trend and more importantly the known index tumor can be monitored objectively with a color-Doppler ultrasound. If there is no evidence of disease progression, he can stay on active surveillance. If not, he should consider an appropriate loco-regional treatment.

## Final Thoughts:

Proper treatment selection is based on accurate staging information. This live on-stage demonstration shows how effective Color Doppler Ultrasound is at detecting cancer abnormalities potentially missed by random biopsy. These two cases illustrate the importance of proper ultrasound evaluation. Without knowing the correct cancer grade and staging information, it would be almost impossible to make an appropriate management decision. □



## Let's Get Real About The Overtreatment of Prostate Cancer

By: Mark Lichty



Eight years ago, at the age of 55, I learned I had prostate cancer. At that time, ignoring three separate doctors' recommendations, I decided to forego surgery. One of my doctors, a urologist, gave me the name of a patient who was on active surveillance. I

contacted Brad Cole and our conversation gave me the courage to try it myself.

My father, who suffered many debilitating side effects from the treatment of his prostate cancer, further motivated my decision to postpone radical therapy in favor of active surveillance. Also, my own study of the medical literature led me to an article that reported impotence in 79% of men after surgery. My perusal of the US Too Inspire Community's website was another eye-opener. I came across countless lamentations from men who had undergone surgery asking for help with managing their treatments' side effects. "I Made a Mistake" was a common thread.

My prostate cancer roller coaster started with the PSA test. When my PSA doubled in a year, a biopsy was recommended. The results came back Gleason 6. I chose active surveillance and started monitoring my PSA quarterly. However, over time I have learned that PSA is a fairly crude cancer monitoring tool. A rising PSA could be from cancer, but it can also be indicative of an increase in prostate size, recent sexual activity, or even riding a bike.

Even if PSA remains relatively stable, urologists often call for periodic biopsies. Biopsies themselves can incur profound risks. I have known several people who have been hospitalized with infections

from biopsies. The procedure calls for punching through the wall of a contaminated intestine with 12 needles into the prostate. Ouch. Furthermore, several studies now indicate that repeated biopsy can degrade erectile function.

Fortunately, imaging methods such as multiparametric magnetic resonance imaging (MRI) or color Doppler ultrasound can help determine if cancer is spreading without incurring any risk of infection. I have experienced both and was satisfied with the approaches. Most urologists require annual biopsies for their patients on active surveillance. I choose a different route with better imaging.

### "I Made a Mistake!" was a common thread.

No matter which treatment route a patient selects, there is always the possibility of recurrence. Those who are treated still require PSA monitoring. In one sense, every prostate cancer patient is on surveillance. At least one study indicates that the anxiety level for those being monitored with PSA testing after treatment is about the same as those who are on pre-treatment active surveillance. These findings parallel my own experience with the disease. Over time I evolved from being panic stricken at time of diagnosis, to being anxious, to being scientifically curious.

Active surveillance patients benefit from the fact that treatment technology is advancing at a rapid rate. The treatment that I receive today, if I were to decide to do treatment, would be far less toxic than that which I would have received seven years ago if I chose to treat my cancer back then. However, better technology doesn't always equal better treatment results. The NY Science Times on March 26, 2013 carried an article entitled "Salesmen in The Surgical Suite" which revealed that robotic surgery may be oversold, and may have no advantage over conventional surgery.

Some advancing technology takes big steps forward in patient care. As an example of this, I have benefited from technological progress for treating my big prostate gland. My once walnut sized prostate gland grew to a small apple size and shut off my urethra holding my urine hostage in my bladder. I passingly considered having my prostate removed to avoid the issue in the future. Instead, I opted for green laser therapy which is a fairly recent technological advance. It opened up the urethra and was done on an outpatient basis.



For me, the apathy towards active surveillance in the medical community is discouraging. For years I have been attending an US Too Support Group, an organization comprised of selfless individuals trying to help men find their way through the morass. Men are generally recommended to opt for intervention, not active surveillance. For as long as I can remember, I have been the only untreated person in my group. Conversation at these meetings invariably revolves around treatment choices or issues with impotence or incontinence.

We have been able to put a man on the moon and create smart phones that would have once taken up a room full of computing power. Why can't we nail the monitoring issue and promote active surveillance in such a way that low-risk patients will opt for it? If we can change the way the world looks at low-risk prostate cancer, thousands of men will choose monitoring, improve their quality of life, be spared from severe side effects, and save billions of dollars wasted on unnecessary procedures. No one should have to suffer the diminished quality of life that my father did.

Recently, the U.S. Preventative Services Task Force has attempted to cut down on overtreatment by recommending against the use of PSA for screening. The Task Force's recommendation was based on the fact that survivability was about the same whether men were treated or untreated. However, the task force recommendation has been criticized because missing aggressive prostate cancer can be fatal.

In my case, had I not been tested and learned I had cancer, I would have continued blithely along making no life style changes. The knowledge that I had cancer spurred me on to doing voluminous research. I ended up on a primarily plant-based, living food diet. My last MRI found no detectable disease. I feel that my knowledge of my cancer was a blessing that profoundly affected my well being beyond just cancer. However, it is a bit of an odd tension that is created here, as I am a proponent of testing so men can better make a decision, but am deeply concerned that that testing will lead to panic which will lead to overtreatment. □

*See references online*



# A DOCTOR'S JOURNEY PURSUING ACTIVE SURVEILLANCE

**Ferd Becker, M.D. - PCRI Educational Facilitator**

I am a plastic surgeon. My father died of prostate cancer at 85 and two of my uncles had prostate cancer. This has motivated me to spend several years studying the disease and taking various supplements to prevent it, knowing that I am at a greater risk because of this history. For many years my PSA was stable. During that time, my case was monitored by Dr. Stephen Strum, the cofounder of the Prostate Cancer Research Institute.

However, in April 2011 my PSA rose to 5.47 and a biopsy showed a small area of Gleason 3 + 3 = 6 in the *left* base of the gland. This biopsy also caused a serious infection which I will discuss further below. After discussing my case with my urologist, we decided that active surveillance would be the best option. Things were going well until I got a second opinion from a radiation oncologist. He ordered an MRI of my prostate. He interpreted the



Dr. Ferd Becker

results as showing "extensive disease, with cancer involving the capsule and neurovascular bundle extending almost to the seminal vesicle on the left and possible rectal invasion on the *right*." To say the least, I was upset. He followed the MRI with a color Doppler ultrasound. On

this study, he saw "extension of the tumor outside the capsule on the right side involving the neurovascular bundles and close to the seminal vesicles with additional tumor on the right extending down to the rectum." He strongly recommended external beam radiation followed by seed implantation. In addition, he insisted that I had to undergo immediate hormone therapy.

Now I was even more upset! In a single afternoon my diagnosis had been transformed from having an incidental cancer to locally-advanced, aggressive prostate cancer. Fortunately, the people on the PCRI Helpline had coached me to not allow

concerns about offending anyone limit me from seeking a second opinion. The following week my wife and I traveled to Virginia to visit Dr. Snuffy Myers.

Dr. Myers noticed a discrepancy between the very favorable biopsy and unfavorable imaging findings. He suggested that I undergo another color Doppler, this time with a Dr. Duke Bahn in California. Two weeks later, Dr. Bahn's study documented a single 7 mm lesion that was nowhere near the capsule suggested by my previous imaging results. According to his findings, I was still an excellent candidate for active surveillance.

In the meantime, I called the PCRI Helpline and asked Jan Manarite to help me work through some of these issues. She suggested I call and speak with the radiologist who read my MRI. The conversation with the doctor was shocking. It turned out that *my images had been mistakenly switched with those of another patient seen on that same day!* My scan, the correct one, only showed a single lesion in the right base and no extension outside the capsule. However, this conversation did not clarify why he thought the color Doppler scan also showed cancer outside the gland.

Still shaken, I decided to obtain an additional, independent evaluation at Johns Hopkins. So in April 2012 I had another multiparametric MRI that confirmed the favorable findings of Dr. Bahn. Finally, I felt a sense of confidence and relief.

Most centers recommend that men on active surveillance schedule a prostate biopsy every few years to "keep an eye on things." However, as I mentioned above, an infection from my first biopsy had previously landed me in the hospital. For that reason, when it became time to consider a repeat biopsy, I selected a center that was offering MRI-guided biopsy through the area between the legs called the perineum. By avoiding the rectum this type of biopsy avoids the primary source of infections, antibiotic resistant E-coli (see August 2011 Insights for more information). Dr. Kemal Tuncali at Brigham and Women's Hospital in Boston, did a 6-core *transperineal* targeted biopsy in October of 2012. The results matched my first biopsy closely. The Gleason was 6 and only a very small amount of tumor was in the specimen.

Through my own research and the guidance of my physicians, I started Avodart mid 2011. Since being on Avodart the PSA had dropped from 5.47 to 1.48. My gland that started at 95 cc has been reduced to 70 cc. My plan is to continue to follow up with PSA readings every three months, get a multi-parametric MRI once a year and avoid any more biopsies unless PSA or imaging indicates a significant change. I will also continue my regimen of supplements and diet as encouraged by Dr. Myers and the recent advice in *Insights* on "Self Care" (See February 2013 Insights).

I am writing this article because I believe others need to be reminded how important it is to maintain control of their own treatment by being informed, double-checking all reports, seeking second and third expert opinions, and obtaining the best care. You can't be too well informed. Accurate knowledge will empower you to make wise healthcare decisions.

Out of gratitude I have decided to join the PCRI Helpline to give back. My goal is to help those fighting prostate cancer much in the same way that Jan Manarite, Dr. Mark Scholz and rest of the PCRI team have helped me. If you feel so inclined, please contact me; I am just a phone call away. □

**CALL OUR HELP LINE ANYTIME!**  
**1 (800) 641-PCRI (7274)**



# A Fresh Look at Prostate Cancer Advocacy

By: Peter Scholz

This past September, hundreds of advocates and prostate cancer patients gathered in Washington D.C. for the annual ZERO Prostate Cancer Summit. ZERO is a national non-profit organization whose mission is to raise awareness for prostate cancer. This year we partnered with them to host our second ZERO Prostate Cancer Run in Southern California.

At this annual summit, the intent was to bring awareness of prostate cancer issues to the attention of the government, particularly in the wake of the Task Force’s recommendation to forgo routine PSA screening. The objective was to meet with government representatives and senators to raise awareness for Prostate Cancer and the need for continued support for funding Prostate Cancer research.

I recently joined the PCRI back in August, fresh out of UCLA with a degree in English. Starting out, I was only vaguely familiar with issues in the prostate cancer world and knew only as much as my dad, Dr. Mark Scholz, would mention in passing over dinner. As it is a writer’s responsibility to know the audience, what better way to learn than to be fully immersed in an event filled with patients and advocates who share a passion for bringing to light issues that affect so many patients and loved ones.

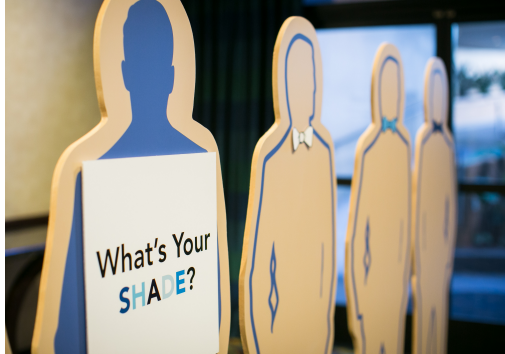
I was eager to accompany our Senior Educational Facilitator, Jan Manarite to the Summit this year. On the first day of the event, we met in D.C. set up our exhibitor table and discussed our objectives for the meeting. Jan encouraged me to speak with the other attendees and hear their stories to get a sense of their concerns. I attended the first-timer’s meeting to get a sense of what I should expect. I began to realize the range of people that prostate cancer affects.

Later that day ZERO had a reception scheduled in the Hart Senate building where all of the attendees had the opportunity to mingle with some of the congressmen. Senator Jeff Sessions addressed the group in a compelling keynote speech expressing strong criticism for the Task Force’s recommendation and encouraged all of us to take action and fight for favorable government legislation. At this gathering I had the opportunity to speak with other advocates from all across the states as well as representatives of the pharmaceutical world.

The next day the attendees had a full schedule of meetings and breakout sessions that gave suggestions on how people can become more involved in prostate cancer research and fundraising. Jan was asked by Kevin Johnson of ZERO to help lead the breakout sessions about getting involved in research. I chose to attend the sessions that briefed the attendees about what to expect when meeting with government representatives and senatorial staff.

On Thursday, a total of 117 meetings took place between the summit’s attendees and government representatives. Patients and advocates had the opportunity to share their stories with their representatives and discuss where they stood on government legislation concerning prostate cancer.

Overall I was blessed with the opportunity to directly converse with those affected by the disease, as well as learn important concepts about activism and fundraising. The event was well structured and informative. I am thankful for what this opportunity has taught me. □



**SAVE THE DATE!**  
**2014 Prostate**  
**Cancer Conference**  
**September 5-7, 2014**

Conference Agenda*	
Laurence Klotz, M.D., FRCS(C)	Active Surveillance for Low-Risk Prostate Cancer
Maha Hussain, M.D.	Advanced Prostate Cancer
Anthony Zeitman, M.D., MBBS	Intermediate and High Risk Disease
John Mulhall, M.D.	Sexual Complications of Treatment
Klotz, Hussain, Zeitman, Mulhall	Round Table
Mark Moyad, M.D., MPH	Diet & Dietary Supplements and Prostate Health
Snuffy Myers, M.D.	Immune Therapy
Mark Scholz, M.D.	Treating PSA-Relapsed Disease

\*Subject to change

**Mark your calendars,**  
**We'll see you next year!**





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