Informed Prostate Cancer Support Group Inc.
"A 501 C 3 CORPORATION ID # 54-2141691"

AUGUST 2011 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142
Phone: 619-890-8447 Web: www.ipcsg.org

We Meet Every Third Saturday (except December)

Thursday, August 11, 2011 Volume 4, Issue 6

Officers

President: Lyle La Rosh,
Vice President : Gene Van Vleet

Additional Directors

Dr. Dick Gilbert
John Tassi
George Johnson

Steering Committee

Judge Robert Coates
Victor Reed
Carlos Richardson
Robert Keck, Librarian
Bill Manning
E. Walter Miles
Jerry Steffen
Robert Werve, Treasurer

Next Meeting August 20th 10:00AM to Noon

Meeting at

Sanford-Burnham Auditorium

10905 Road to the Cure, San Diego CA 92121

SEE MAP ON THE LAST PAGE

What We Are About

Our Group offers the complete spectrum of information on prevention and treatment. We provide a forum where you can get all your questions answered in one place by men that have lived through the experience. Prostate cancer is very personal. Our goal is to make you more aware of your options before you begin a treatment that has serious side effects that were not properly explained. Impotence, incontinence, and a high rate of recurrence are very common side effects and may be for life. Men who are newly diagnosed with PC are often overwhelmed by the frightening magnitude of their condition. Networking with our members will help identify what options are best suited for your life style.

Be your own health manager!!

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The July meeting was the best ever! Over 140 people attended and there were 24 newcomers—the most ever for both!

Our speakers were Dr. Duke Bahn and Dr. Osamu Ukimura who are leaders in the development of new technologies for the diagnosis and treatment of our disease.

Dr. Bahn focused on Active Surveillance as a viable treatment alternative. In the PSA screening era the risk of over detection is high and only a small percentage of men with low-risk disease choose Active Surveillance. Patients with low-risk tumors or without extended life expectancy may not benefit from treatment. Active surveillance allows you to delay the treatment as long as reason-

Video DVD's

DVD's of our meetings are available in our library for $10ea. Refer to the index available in the library. They can also be purchased through our website: http://www.ipcsg.org. Click on the 'Purchase DVDs" button.

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able to avoid collateral damage and loss of function while not losing the window of opportunity for successful local therapy. The following list defines Dr. Bahn's "Perfect 10" requirements to be a good candidate for Active Surveillance.

1. Gleason 6 or less, may be up to 7=3+4
2. PSA less than 20 ng/ml. (PSA Density <0.15)
3. 4Stage: T1c-T2a, T2b with co-morbidity
4. Positive Biopsy Cores: less than 1/3 of cores
5. Percentage of tumor invasion: less than 50%
6. PSA doubling time: >2 yrs, prefer >3 yrs
7. Tumor neovascularity on color Doppler ultrasound: 2+ or less
8. Tumor volume on color Doppler ultrasound: less than 1cc
9. Urine PCA-3 gene test: less than 25 (tumor ,0.5cc)
10. Ploidy: Diploid

One can readily see that the information required is far beyond that required or even understood by many urologists. More detailed information and slides included in Dr. Bahn's presentation are included in the July meeting DVD.

Doctor Ukimura is a urologist who firmly believes that the education of urologists needs to be expanded and improved to more modern methods. 218,000 men were diagnosed in 2010 and 32,000 died. Among approximately 1.5 million prostate biopsies per year, a positive case could be found in every 6-8 biopsies. Since the majority of those with early prostate cancer will not die there should be serious concern that more PSA testing and more numbers of prostate biopsies lead to over-detection and over-treatment. Over-diagnosed patients my not benefit from the traditional (invasive) treatments and may be exposed to unnecessary anxieties due to becoming a cancer patient and to potential treatment-related side effects. Further there may also be physiological and financial burdens involved.

If the cancer is confined to the prostate or spread only to regional lymph nodes, the 5 year survival rate is very high. Prostate cancer is multifocal. Traditional treatments have treated the entire prostate gland with significant side effects. To minimize side effects, the desire is to move away from treating the entire gland and rather treat the clinically significant cancers (foci). Dr Ukimura presented graphic illustrations of the use of transrectal ultrasound (TRUS) that can be enhanced by Doppler, Elastography, 3D, Contrast, MRI and others. They are high resolution, safe, cost friendly and convenient. They are urologist friendly as well and can be available in both clinics and operating rooms. However, they are highly operator dependent and there is a significant learning curve. There is a lack of effective education programs for urologists. One of Dr. Ukimura's goals is to make better education available to them.

A TRUS guided biopsy can more effectively be used to identify cancer foci and determine the need for treatment of only those dominant cancerous foci that need to be treated. The less significant foci can be monitored with Active Surveillance. Dr. Ukimura is pioneering technology that is developing 3D images that can be used for mapping biopsies and even for guiding focal cyrotherapy to only the significant foci rather that the customary treatment of the whole gland. In this manner, side effects are minimized.

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More detailed information and slides of Dr. Ukimura's presentation are also included in the July meeting DVD which can be purchased for $10 from our library or through our website: www.ipcsg.org.

Future Meetings

August 20, 2011. Topical discussions and break-out sessions by treatment preference.

January 21, 2012. Dr. Richard Lam, Prostate Oncology Specialists-Review and update on prostate cancer treatment.

If you have leads to speakers related to the interests of our group please contact: lyle@ipcsg.org or gene@ipsg.org

NOTEWORTHY ARTICLES

Important News on Active Surveillance

BY MARK SCHOLZ, MD

(Reprinted from Prostate Snatchers Blog)

For men with prostate cancer on active surveillance or ("watchful waiting," as it is often known), new and compelling data from a large study called the "PIVOT Trial" was presented at the annual meeting of the American Society of Urology this May. In this trial, which started in 1994, 731 men volunteered to get either watchful waiting or immediate surgery based on a coin flip. The goal of the trial was to determine if immediate surgery prolongs life compared to watchful waiting.

The men in the study had a median PSA of 7.8. One strength of the study was the fact that 75% of the men were diagnosed after biopsy for a rising PSA (as opposed to feeling a lump on the prostate). This means that these study results can be more easily compared to the situation men face in this modern era. The weakness of previously published watchful waiting studies was that they were done on men with more advanced disease, cancer that was diagnosed by feeling an abnormality on the prostate gland during a digital rectal exam (DRE)—so called palpable disease, a situation that is far less common these days.

The breakdown of the risk categories of the men participating in the study was similar to what is commonly reported in men with newly-diagnosed prostate cancer in the modern era:

- 43% *Low-Risk*
- 36% *Intermediate–Risk*
- 20% *High-Risk*

The surprising finding, after 12 years, was that there was no difference in survival between surgery and watchful waiting in the Low-Risk *or in the Intermediate -Risk group.* On the other hand, men who were in

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the *High-Risk* category did benefit with improved 12-year survival when treated with immediate surgery compared to the men with *High-Risk* disease who did watchful waiting.

The results of the Pivot Trial are very important because up till now only men with *Low-Risk* prostate cancer were thought to be safe candidates to do watchful waiting.

We eagerly await the final publication of all the data from the PIVOT trial since expanding the recommendation for watchful waiting to men with *Intermediate-Risk* disease would essentially double the number of men in the United States who would be eligible for monitoring. Additionally, this new discovery that men with *Intermediate-Risk* prostate can be safely monitored provides even stronger assurance to men with *Low-Risk* disease who have been experiencing trepidation about forgoing immediate treatment.

The Robots Have Landed

By Ralph Blum

(Reprinted from Prostate Snatchers Blog)

Nearly every industry on God's good earth has become mechanized in some form or another over the past 200 years, and the Prostate Cancer Industry—yes, it's an industry, folks—is no exception. Enter the da Vinci Robot.

In 2009, according to Intuitive Surgical Systems (the company that manufactures the da Vinci robot), 85,000 American men, 86% of those who underwent prostate cancer surgery that year, had robot-assisted surgery. Furthermore, roughly 75% of today's urologists are being trained in robotic surgery, and the da Vinci robot is now found in more than 1000 hospitals and clinics across the country, snipping, slicing and dicing the family jewels. These are fairly staggering statistics. So let's examine this infatuation with the robot.

Undoubtedly robotic surgery is currently the most advanced treatment option for men with localized cancers who still belong to the "just cut it out" school of prostate cancer. In the hands of an experienced robotic surgeon, you will experience less blood loss, less pain, a shorter hospital stay—usually only one or two nights—and faster recovery. Some men claim to be teeing off in a week. All great selling points. But what is the downside?

Obviously recovery varies from man to man depending on age, general health, and cancer stage. However it is not at all clear whether the long-term results or survival rate after robotic surgery are better, worse or the same when compared to the traditional open prostatectomy. And despite the marketing frenzy surrounding robotic surgery, studies to date show that rates of incontinence and impotence are virtually *identical* to the results obtained with the traditional methods, and ultimately depend on the skill and experience of the surgeon.

According to a recent study, a year after robotic surgery only one out of four men had recovered the ability to have intercourse. Another new survey showed that half of the men who undergo robotic surgery experience a greater incontinence problem and less sexual function than they anticipated.

A radical prostatectomy, whether traditional or robotically assisted, is a complex and intricate surgery. The prostate is located within millimeters of the bladder and the rectum, giving the surgeon very little room in which to work. And blood pooling in the operative field makes it seriously challenging to avoid damaging the nerves—thinner than a human hair—that run along each side of the prostate and control erections. Even in the hands of the most highly skilled surgeon you are fortunate if you achieve what Dr. Peter Scardino, Chief of Urology at Memorial Sloan-Kettering calls a "Trifecta:" positive margins

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(meaning no cancer left behind after the operation), maintained potency, and preserved urinary control. However, in less skilled hands such good results are iextremely unlikely.

Remember, it's the surgeon *behind* the robot who is actually performing the operation. Even the best surgeons report impotence rates of up to 50% and incontinence rates of 10%. And not all surgeons are created equal. Too often, operations are being performed at community hospitals by surgeons without sufficient experience.

Opinions differ widely about how many robot-assisted operations a surgeon needs to perform in order to be considered "proficient." Some researchers estimate as few as 150 to 200 procedures. Others claim that as many as 1,600 operations are required in order to gauge with 90% accuracy how much tissue surrounding the prostate needs to be removed to get all the malignant cells.

Bottom line: A good outcome depends on the experience and skill level of your surgeon. So choose carefully. And before you decide, be sure to ask how many robot-assisted prostatectomies he has performed. You do *not* want to be part of your surgeon's learning curve.

The lure of the robot is high-tech glamorous. The promise of a less invasive surgery with faster recovery time, plus the expectation of a better long-term outcome (based more on marketing hype than on actual studies), has almost doubled the number of radical prostatectomies performed each year in this country. So before you make what is sure to be a life-changing decision—and especially if your prostate cancer is the low-risk variety or you are 70 or over—don't let all the publicity, or your urologist's bias in favor of robotic technology, persuade you that surgery is your best treatment option.

Data from the recent Prostate Cancer Intervention Versus Observation Study (PIVOT) indicates that a vast majority of the 85,000 prostate cancer surgeries performed in 2009 were simply unnecessary. In other words, most of those men would live just as long without any surgery at all, and would be spared the risk of impotence and incontinence. Clearly men are failing to get the full picture of the risks and benefits of all the different options—Surgery, Seeds, IMRT, Testosterone Deprivation, Hormone Blockade, Focal Cryotherapy, Active Surveillance—before they commit to robotic surgery.

So, yes, the robots have landed. And whatever else is still uncertain, one thing is for sure—they employ first-rate Madison Avenue publicists.

Resistant prostate cancer not driven by testosterone as believed

(Reprint from EMax News 7-26-11)

New research finds advanced forms of prostate cancer are not driven by testosterone as previously believed. The finding means targeting a newly discovered enzyme could improve prostate cancer outcomes for men whose disease has spread beyond the prostate gland.

UT Southwestern scientists found advanced cases of prostate cancer evade testosterone, previously thought to stimulate cancer growth.

The finding explains why testosterone deprivation therapy fails to eradicate prostate cancer tumors.

Dr. Nima Sharifi, assistant professor of internal medicine and senior author of the study in Proceedings of the National Academy of Sciences, explains testosterone converts to a more potent male hormone that fuels tumor growth when the disease becomes more advanced.

Dr. Sharifi says, "The general assumption is that the tumor accelerates through testosterone when, in fact, the pathway goes around it to the most potent hormone. We both found the existence of this pathway in models and patients, and have shown that these resistant tumors are clearly driven by this other pathway."

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Understanding what drives prostate cancer means researchers can use different drugs that target the enzyme responsible for converting testosterone into a more potent hormone.

Sharifi explains different drug treatment for prostate cancer …"can be thought of as charting a map of the correct pathway. You have to figure out which way the river flows before you can block the river."

The finding, according to Dr. Sharifi, will change the way prostate cancer is viewed. Treating advanced prostate cancer requires drugs targeting an enzyme that initiates hormone production earlier in the disease.

Testosterone is known to drive prostate cancer. The new finding shows advanced stages of the disease is driven by a different and more potent hormonal pathway that was previously unknown and bypasses testosterone altogether.

HEALTH INSURANCE NEWS

Affordable Care Act gives consumers new tools, makes health insurance market more transparent

Created under the Affordable Care Act, www.HealthCare.gov was launched July 1, 2010, and is the first website of its kind to bring information and links to health insurance plans into one place to make it easy for consumers to learn about and compare their insurance choices. HHS' Office of Consumer Information and Insurance Oversight (OCIIO) worked to define and collect detailed benefits and premium rating information from insurers across the country, and starting October 1, 2010, consumers will also be able to find information about health insurance options such as: Monthly premium estimates; Cost-sharing information, including annual deductibles and out-of-pocket limits; Major categories of services covered; Consumer's share of cost for these services; Percent of people in the plan who pay more than the base premium estimate due to their health status; Percent of people denied coverage from a health plan.

More than 225 insurance companies have provided information about their individual and family plans for more than 4,400 policies, including policies in every state and the District of Columbia. Consumers can search for and compare information on plans available based on age, gender, family size, tobacco use and location.

NOTE

California law requires that you have an annual 30-day period beginning on your birthday during which you may purchase any Medicare supplement coverage that offers benefits equal to or lesser than, those of your current coverage. You are eligible to purchase such plans without regard to your health status, claims experience, receipt of health care or medical condition

The medical insurance committee, comprised of Bill Pitts, Dennis Walker and Gene Van Vleet assists in making choices that provide them the best coverage suitable to their situation The committee cannot be expected to make recommendations for suitable medical coverage but rather should be a resource of information to help you determine what options are most suitable for your situation.

Our committee members are willing to provide you with education and resources.

If you have particular knowledge that would be helpful to our goal of creating a base of information, please volunteer your efforts to the committee. Contact Gene Van Vleet, e-mail gene@ipcsg.org or cell phone 619-890-8447 who may redirect your inquiry to an appropriate person for response.

PLEASE, volunteer your effort to assist our cause.

Announcements

Member and Director, John Tassi continues to develop our new website that we believe is much simpler and easier to navigate. **Check out the Personal Experiences page and send us your story**. Go to: http://www.ipcsg.org

Our brochure provides the group philosophy and explains our goals. Copies may be obtained at our meetings. Please pass them along to friends and contacts.

Ads about our Group are in the Union Tribune 2 times prior to a meeting. Watch for them.

Our Steering Committee meets for lunch, usually at Baci's restaurant (preferred) at noon on the first Tuesday of each month. All members are welcome! Please call Lyle La Rosh at 619-892-3888, to make reservations and to verify location.

Library Announcement

"To all those who have borrowed books, tapes or DVD's please return them at the next meeting" Some copies of the book "China Study" have been donated by Robert Werve. This is very informative reading. Bob Keck Librarian

Snail Mail Recipients Notice!

Snail mail is expensive. E-mail is not. If you have changed to e-mail let us know. Send your information to: gene@ipcsg.org.

More PC Meetings:

The Prostate Cancer Research Foundation (PC-Ref) meets on the 2nd Saturday of each month at Alvarado Hospital, 6655 Alvarado Rd. They start at 10:00 AM for newcomers and at 11:00 AM for every one. Check out the website at: http://www.pcref.org or phone them at (619) 906-4700.

We Need Help

All services for our group are performed by volunteers. As is usual in our type of organization we have a few doing a lot for many. We need people to step up and help in the following areas:

1. Fund Raising. We need help from anyone with any knowledge or willingness to become involved in acquiring grants to support our organization. We need someone to organize fund raising activities.
2. Information Technology. Any techies out there that can help take advantage of the facilities available where we meet--such as live remote conferencing.
3. Assistance with editing and publishing monthly newsletter.

Anyone interested please contact:
Gene Van Vleet, Vice President. 619-890-8447 gene@ipcsg.org
Lyle LaRosh, President 619-892-3888 lyle@ipcsg.org

NETWORKING

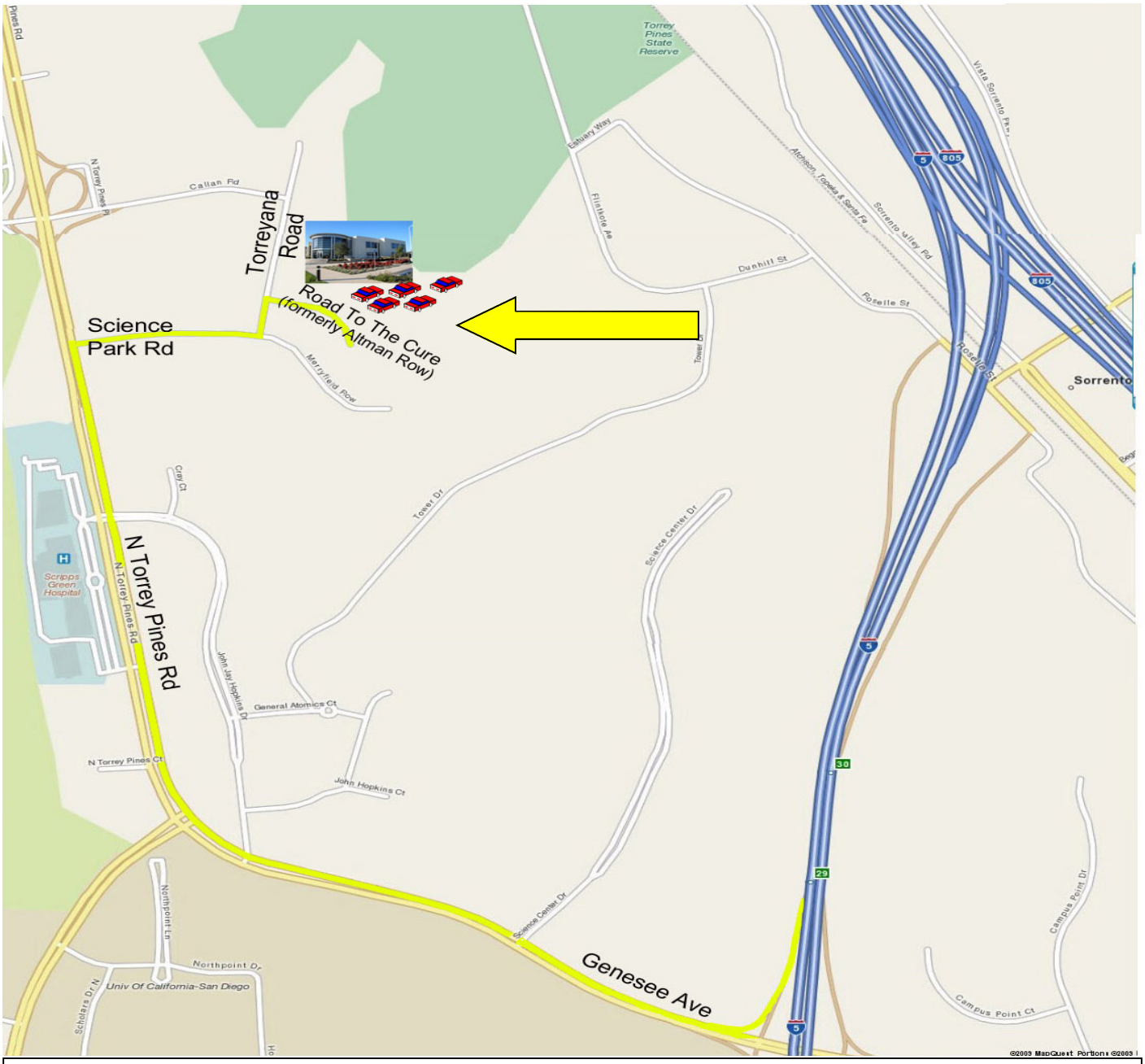
The original and most valuable activity of the INFORMED PROSTATE CANCER SUPPORT GROUP is "networking". We share our experiences and information about prevention and treatment. We offer our support to men recently diagnosed as well as survivors at any stage. Networking with others for the good of all. Many aspects of prostate cancer are complex and confusing. But by sharing our knowledge and experiences we learn the best means of prevention as well as the latest treatments for survival of this disease. So bring your concerns and join us.

FINANCES

We want to thank those of you who have made special donations to IPCSG. Remember that your gifts are tax deductible because we are a 501(c)(3) non-profit organization.

We again are reminding our members and friends to consider giving a large financial contribution to the IPCSG. This can include estate giving as well as giving in memory of a loved one. You can also have a distribution from your IRA made to our account. We need your support. We will, in turn, make contributions from our group to Prostate Cancer researchers and other groups as appropriate for a non-profit organization. Our group ID number is 54-2141691. Corporate donors are welcome!

If you have the internet you can contribute easily by going to our website, http://ipcsg.org and clicking on "Donate" Follow the instructions on that page. OR just mail a check to: IPCSG, P. O. Box 4201042, San Diego, CA 92142



Directions to Sanford-Burnham Auditorium
10905 Road to the Cure, San Diego, CA 92121

Take I-5 (north or south) to the Genesee exit (west).
Follow Genesee up the hill, staying right.
Genesee rounds right onto North Torrey Pines Road.
Do not turn into the Sanford-Burnham Medical Institute or Fishman Auditorium
Turn right on Science Park Road.
Turn Left on Torreyana Road.
Turn Right on Road to the Cure (formerly Altman Row).