Informed Prostate Cancer Support Group Inc.

"A 501 C 3 CORPORATION ID # 54-2141691"

October 2017 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142

Phone: 619-890-8447 Web: http://ipcsg.org

We Meet Every Third Saturday (except December)

Monday, October 16, 2017

Volume 10 Issue 10

Next Meeting
Oct 21, 2017
10:00AM to Noon

Meeting at

Sanford-Burnham-Prebys Auditorium

10905 Road to the Cure, San Diego CA 92121

SEE MAP ON THE LAST PAGE

PROSTATE CANCER - 2 WORDS NOT A SENTENCE

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 PCa 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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Editor: Stephen Pendergast

RECAP OF LAST MEETING

By Bill Lewis

Advances in Radiation Oncology for the Treatment of Prostate Cancer

Brent S. Rose, MD, Radiation Oncology, UC San Diego

Video DVD's

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

The DVD of each meeting is available by the next meeting date. They now include the slides.

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1. Focal Radiotherapy Boost of Dominant Intraprostatic Nodule

Prostate cancer is usually multifocal, with a dominant nodule (tumor), and one or more other smaller tumors. So "whole-gland" radiotherapy has been necessary up to now to treat all of the cancer. Often after radiation, the cancer comes back in the dominant nodule area, so it is hypothesized that that nodule reflects the most aggressive part of the tumor. A new goal is to increase the dose to that highest risk area, without significantly increasing the dose to surrounding tissue. Some details, such as how much boost to give, are still being worked out on a case by case basis. But use of this approach is expected to increase.

2. Treatment Response Assessment with MRI

When a patient is being treated for prostate cancer, it is important to learn quickly whether the treatment is working. This could allow for dose escalation (or even de-escalation), based on whether the response of the tumor(s) to the treatment is favorable or not.

Multiparametric MRI is the best way of imaging localized prostate cancer. The key parameters are T2 (for anatomic detail), Dynamic Contrast Enhancement (showing tumors because of their greater blood supply resulting in fast uptake of the contrast agent), and Diffusion Weighted Imaging (showing areas of dense tissue, which signifies a tumor – and the density correlates with Gleason scores!). At UCSD, an advanced diffusion weighted imaging technique called Restriction Spectrum Imaging has been developed. The anatomic detail of the T2 parameter is overlaid on the DWI result, and this gives a precise understanding of where the tumor is, and is very helpful in planning for focal radiation treatment.

3. Sexual Potency-Preserving Radiotherapy

Erectile dysfunction is one of the most significant complications of prostate cancer treatment. One of the common pathways for escape of the cancer from the prostate is along the nerves of the "neurovascular bundle." So surgery often involves cutting these nerves to get out all the cancer. That negatively affects sexual potency. The (typically smaller) impact of radiation on erectile function is likely due instead to irradiation of the vasculature (blood vessels) of the penis, resulting in decreased blood flow. It's as though the radiation causes accelerated aging, leading to buildup of plaque and less blood flow to create erections.

By directing the radiotherapy appropriately, with the aid of an MRI scan, the blood vessels can be spared much more precisely than in the past when only CT scans (which don't show prostate anatomy well) were used for planning. With this precise targeting, critical normal structures can be avoided, and the need for ADT (hormone therapy) may be avoided or reduced. Although the radiation field typically includes the neurovascular bundle, the nerves are relatively resistant to radiation, so are not adversely affected very much. Sexual potency is more often preserved compared to results after surgery. See European Urology, 72 (2017) 617-624.

4. Treatment of Oligometastatic Disease:

This is prostate cancer with 1-4 metastases, typically in the lymph nodes or bones. Preliminary literature reports suggest that aggressive treatment may improve survival. In a case example given, a bone scan gave (as always) poor sensitivity and specificity, but an F18-Fluciclovine ("Axumin," radiolabeled amino acid) PET scan showed a distinct area that could be treated with radiation. Other agents can also be used in PET imaging, including C-11 and PSMA tracers, but they are not FDA approved, so insurance won't pay for them [but see last month's Q&A for PSMA at UCSF paid for by Medicare]. In the case shown, MRI

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gave very distinct identification of the metastatic lesion, near the prostate, and the patient was treated with stereotactic radiation therapy (a short course of high-dose radiation). In some cases, prostatectomy may be done in addition. ADT may follow for a time, possibly including abiraterone (Zytiga).

UCSD has opened a study for cancer patients with high-risk or known metastatic disease, with a goal to test the accuracy of whole-body MRI to identify sites of metastatic disease.

Questions:

If on Lupron, can one use the advanced diagnostic tests (PET with tracer)? Yes, but … Lupron tends to put the cancer to sleep, so it's harder to see the lesions. It's still possible to find them if looking carefully.

When should one use proton therapy instead of IMRT? Studies are underway, but in general results are very similar. Side effects are about the same. Protons don't pass all the way through the body, so that's an advantage for some cancers, like brain cancer or the spine (but not demonstrably so yet for prostate cancer). It takes a very powerful (large!) machine to accelerate the protons, and this physically interferes with following the therapy by daily imaging. However, improvements are being made.

PIRADS scores vs. Gleason Scores? Not equivalent, but they tend to track together.

MRI after surgery – does it correlate with PSA level? Usually MRI after surgery is not very helpful, because any remaining tumor is likely very small and hard to see, especially in and around scar tissue. Axumin or C-11 scan is likely to be more sensitive in that case.

SpaceOAR (gel injected between prostate and rectum before irradiation) pros and cons? Great in theory, but how much it really matters, and what the side effects are, are still not fully determined. A very slight benefit has been shown in published studies. But, a few patients got fistulas. That's serious, though rare, and not proven if caused by the injection rather than something else. At UCSD, they find the gel is not necessary because the rectum is not significantly damaged even when the gel is not used. Note: It's not covered by some insurance, and costs up to $5,000.

Qualifications for the whole-body MRI research study? They are very broad: having high risk for metastatic disease (newly diagnosed) or known metastatic disease are the only requirements. Also, patients with recurrence (elevated PSA) after surgery are eligible.

What to do if one has Gleason 6 and PSA = 5 with two cores positive? You would be unlikely to find anything with MRI, but could get the scan to be sure that a more aggressive tumor wasn't missed. Dr. Rose said this member is a candidate for active surveillance ... and continuing to attend IPCSG meetings! But he should also consider talking to a radiologist and to a surgeon. If more cores were positive, then the advisability of an MRI would rise.

MRI after surgery and radiation? Not likely to find anything if the PSA is, say, 0.2, but you may see something if it is 2 or more. A whole-body MRI might be helpful, to look for metastases.

With a rising PSA after external radiation, with Gleason 7, and apparent local recurrence in the prostate, when should one "pull the trigger?" Surgery is likely to cause incontinence. Brachytherapy (radioactive seeds) or cryotherapy may be appropriate. Whole body imaging may be useful to look for metastases. Decisions depend on the details of the case. Not a clear-cut path forward that would fit all such cases.

Having recurrence after surgery, in the seminal vesicles, with radiation planned for the new tumor – should Lupron be used before radiation, to shrink the tumor? It is likely to shrink the tumor, but it's not known if and how much help that would be, for avoiding irradiation of the bladder.

How relevant is the patient's age – from a member who is 87? His PSA is 0.3, and his doctor recommends

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discontinuing Lupron. Dr. Rose advised him to make his own decision, considering quality of life and length of life.

Testosterone supplementation? Recent consensus is that if the PCa stays low after initial treatment (such as surgery and/or radiation), that supplementation to a normal testosterone level to improve quality of life, may be acceptable (and not fuel the cancer too much). This recovery of the testosterone level occurs naturally in younger men, so supplementation doesn't seem too dangerous in older men. If the cancer is coming back, the testosterone supplementation probably will "fuel the fire" a little bit. That is likely to make the PSA rise faster, and result in going back on Lupron faster. It's a personal choice.

If you have external beam (e.g., IMRT) radiation, and the cancer comes back, can you get radiation again? Yes, but the side effects are high if more IMRT is given. Proton therapy would likewise not be advised. Your body "remembers" that you had radiation. The first dose is usually as high a dose as the body is likely to tolerate. But cryotherapy, brachytherapy (seed implants) or SBRT (very focused radiation) are possibilities that may limit the side effects.

Tumor recurrence in the same spot five years after IMRT and ADT – what to do? The member had heard there is a two-part radiation treatment. Dr. Rose surmised that this was a reference to a brachytherapy boost, where seeds are implanted in the prostate to allow a much higher dose to the tumor than can be given by external radiation (see also the next question response below). Other options are cryotherapy, SBRT (but rare in this type of case), and nanoknife (Note: a talk on Nanoknife, also called IRE – Irreversible Electroporesis – was given at the IPCSG last September. The video is available through the group website, and a summary of the talk is available by contacting this author at lewis.bill@gmail.com)

More info on brachytherapy? Often used at UCSD. One situation is for first treatment after active surveillance suggests some treatment is advisable. It is a one-day procedure with good efficacy, and has low side effects. Affects the urinary tract somewhat, but spares the erectile function. The second situation is use in combination with external radiation and hormone therapy, with published results showing good control of cancer within the prostate. The combination gives a high dose in the observed tumor, plus a surrounding margin of radiation to eliminate other small tumors.

Usefulness of MRI-guided biopsy – required before brachytherapy? Not "required" for it or other therapies, and thus may not be paid for by insurance, but he would choose it if newly diagnosed, to gain the best understanding of the disease status.

Is RSI-MRI better than mpMRI? Dr. Rose thinks so. It gives better identification of high-grade tumors, and helps avoid being fooled by things that are not tumors. Not 100% better; more like 20% better.

Differences between locally available proton therapy, and that at Loma Linda? Here, we have IMPT (Intensity Modulated Proton Therapy), which is more sophisticated than Loma Linda center's proton therapy.

See: Scripps Health distances itself from proton therapy center - Modern Healthcare business news, research, data and events

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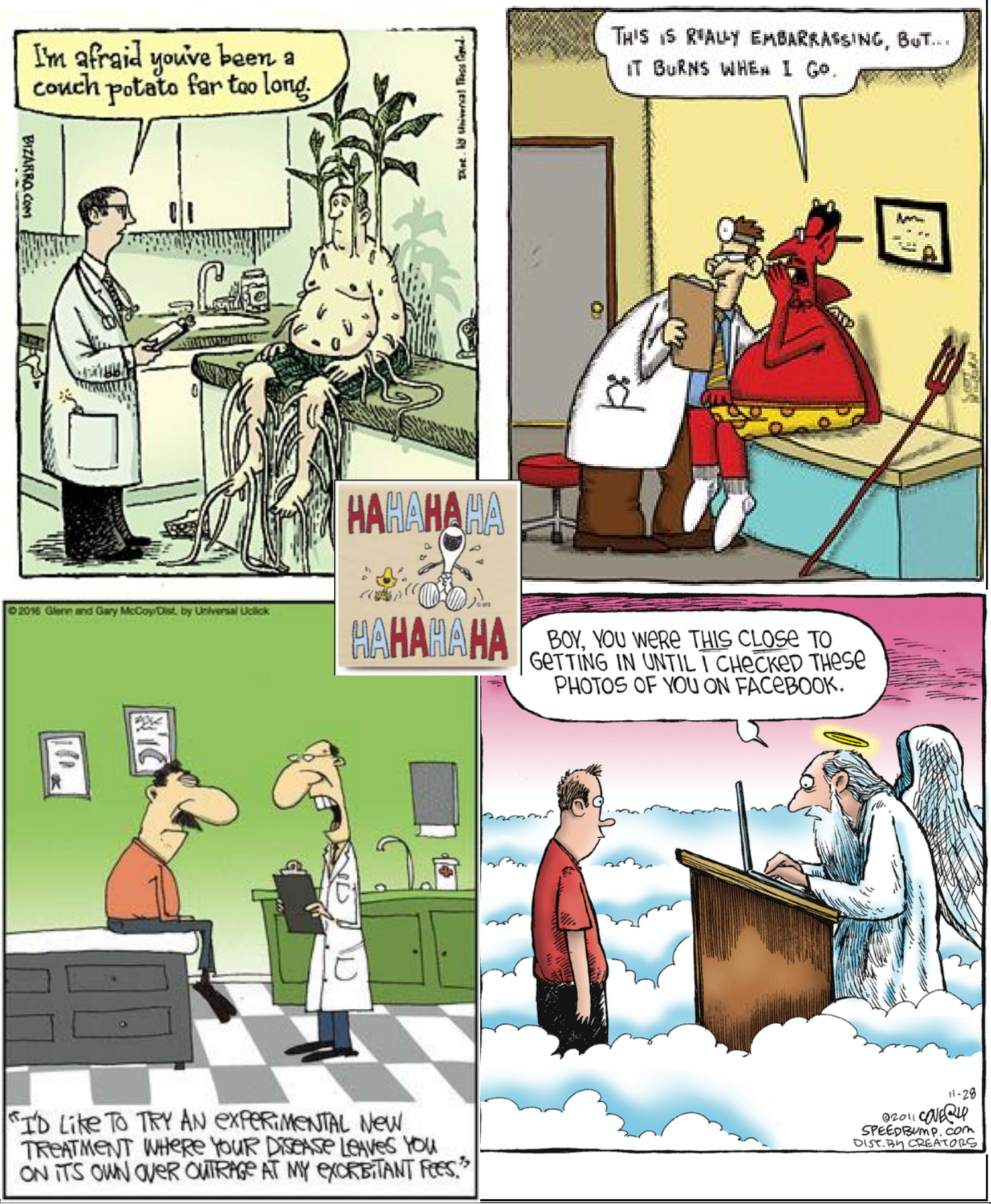
ON THE LIGHTER SIDE



FUTURE MEETINGS

- October 21, 2017—**ADVANCES IN DIAGNOSTICS** Fabio Almeida, M.D.
  As Medical Director of Phoenix Molecular Imaging and Southwest PET/CT Institute in Yuma, AZ, Dr. Almeida oversees clinics in Phoenix, Yuma, and Tucson, providing his extensive clinical expertise in PET/CT imaging. He continues his research, focused on applied medical informatics with emphasis on imaging and networking systems, optimization of fusion technology, and volumetric tumor assessment for radiation therapy planning. He actively participates in several oncology and neurologic clinical trials and is the principal investigator for a novel Carbon-11 PET agent for prostate cancer imaging.
- November 18, 2017—**ADVANCES IN IMMUNE THERAPY** Richard Lam M.D.
  A board-certified internist and oncologist, **Richard Lam, MD**, has been specializing full time at Prostate Oncology Specialists in the treatment of prostate cancer since 2001. He is the director of clinical research. Dr. Lam has written numerous articles based on his research. He is an active member of the American Society of Clinical Oncology and the American Society of Hematology. Dr. Lam continues to promote prostate cancer awareness and education by giving lectures at various medical conferences and prostate support groups throughout the country. He is particularly interested in utilizing state-of-the-art therapeutics for advanced prostate cancer.
- **December—no meeting, next meeting in January.**

INTERESTING ARTICLES

How to Avoid Buyer's Remorse After Your Prostatectomy

https://prostatecancernewstoday.com/2017/10/06/prostate-cancer-how-to-avoid-buyers-remorse-after-your-prostatectomy/

October 6, 2017 by Rick Redner

In Columns, Living & Loving with Prostate Cancer.

According to the National Cancer Institute, nearly half of all men diagnosed with prostate cancer in the U.S. choose surgery.

A study published in the journal *Research and Reports in Urology* found that the rate of prostatectomy-related regret increases over time, with up to 47 percent of men reporting regret five years after surgery.

My favorite article about regretting prostate surgery is titled, "I Want My Prostate Back." I suspect most men who've had prostate surgery can relate to the following paragraph from that article:

"Now, almost 2 years later, I'm not going to say, 'thank god they caught it in time … I'm so blessed, each new morning is a miracle…Blah blah blah blah.' No, what I'm thinking is more along the lines of: I want my prostate back." *https://www.menshealth.com/health/coping-with-prostate-cancer*

I've spent some time wishing I had my prostate back. Did you?

Multiple reasons explain why a significant number of men who choose robotic surgery experience buyer's remorse. The first source of buyer's remorse comes from believing exaggerated and unsubstantiated claims.

A 2011 study by Johns Hopkins School of Medicine found that 164 hospital robot-surgery websites surveyed "overestimate benefits, largely ignore risks and are strongly influenced by the manufacturer."

A second source of buyer's remorse comes from miscommunication between the surgeon and the patient about regaining urinary control. When a surgeon states that more than 90 percent of his patients regain urinary control, what are they saying and what's left out?

Some surgeons define urinary control as using one pad a day. Others say living without a pad is regaining urinary control. What the patient hears is that his pre-surgery level of urinary control will return.

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What's left out of the discussion is the issue of leaking. Statistically, I'm counted among those who regained urinary control because I don't use a pad. In order to live pad-free, I'm constantly vigilant about the state of my bladder.

If my bladder is full, a sneeze, a cough, or lifting something heavy will cause me to leak urine. The volume of urine I leak depends on the fullness of my bladder. It's something I constantly monitor during my waking hours. This doesn't feel like a return of urinary control — it's more like leak management.

There's another place I leak urine and I hate it. Every man who agrees to prostate surgery should receive written information about this possibility. If you leak urine before or during orgasm you're coping with climacturia.

According to the International Society for Sexual Medicine, "An estimated 22% to 43% of men experience climacturia after prostatectomy. It can be a distressing situation for both men and their partners."

The shame, embarrassment, or disgust about leaking urine during sex are deal breakers for many couples. Couples give up their sexual relationship. Some single men give up on dating and marriage.

Climacturia is one of the factors that explain why Dr. Claus Roehrborn, a professor and chairman of the urology department at University of Texas Southwestern Medical Center in Dallas, told the *Australian Financial Review*: "A year after a radical prostatectomy, 15 per cent of men will still be leaking urine in some way, and of those who enjoyed full potency before the operation, only one in six will have resumed sexual activity."

Pause for a moment and wonder why so many men post-surgery who are capable of achieving an erection give up on sex.

The third source of buyer's remorse occurs during the discussion about the return of erectile functioning. Men enter this discussion thinking that a return of sexual functioning means a return to their pre-surgery abilities and sex life. Unfortunately, that's not what it means.

Here's a list of potential post-surgery changes:

- All prostatectomies cause the loss of ejaculation. No one told me this would happen. Initially, this loss took all of the pleasure out of experiencing an orgasm. I experienced this as a devastating loss.
- The majority of men will experience a temporary bout with impotence. Few of these men and couples receive information, help, or support with an issue that causes an earthquake in their relationship.
- Some men require a vacuum pump, ED medication, or penile injections in order to achieve an erection.
- Changes in the intensity of your orgasm. For some it's more intense, for others like myself, it's severely diminished.
- Penile shrinkage. Some men experience a noticeable reduction in the length of their penises.
- Climacturia is defined by leaking during orgasm.
- Changes in the desire for sex. Some men experience a diminished desire for sex, and some lose their desire for sex.
- A change in the level of hardness. Many men achieve a hardness that allows for penetration, but their level of hardness is nowhere near pre-surgery levels.

These changes can diminish a man's self-esteem, manhood, and sexuality. Relational difficulties also arise. Whether you choose surgery or a different treatment modality, it's important for you to understand the quality of life issues and changes you'll experience with each of your treatment options.

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Exercise May Lower Prostate Cancer-Specific Mortality

http://www.medscape.com/viewarticle/886209 Gerald Chodak, MD — October 05, 2017

Today's topic is the potential value of physical activity for men diagnosed with prostate cancer. The American Heart Association, the American College of Sports Medicine, and the American Cancer Society have all recommended that adults engage in at least 75 minutes of vigorous activity or 150 minutes of moderate activity weekly.[1,2]

The Prostate Cancer Prevention Trial (PCPT) began in 1993 and followed men with nonmetastatic prostate cancer through 2012. Wang and colleagues[3] used data from the PCPT to examine the relationship between recreational physical activity and causes of death from prostate cancer and other diseases. This analysis included approximately 7300 men who reported exercising before the diagnosis of prostate cancer and 5300 men who exercised after diagnosis. *They assigned different metabolic levels of activity (metabolic equivalent hours) to different exercises, such as jogging, dancing, biking, walking, and swimming.*

Intensity	Type of recreational physical activity	MET value hrs/hr
Moderate	**Walking**	3.5
	Bicycling	4.0
	Aerobics	4.5
	Dancing	3.5
Vigorous	**Jogging or running**	7.0
	Lap swimming	7.0
	Tennis or racquetball	6.0

The investigators found that for men diagnosed with low-risk disease who had exercised before the diagnosis of prostate cancer, engaging in 17.5 hours or more of metabolic activity per week resulted in a significantly lower risk of dying from prostate cancer, compared with men who engaged in less than 8.75 hours of metabolic activity per week. Low-risk disease was defined as stage T1 to T2 and a Gleason score of 2 to 7. For men with high-risk prostate cancer, there was no association with physical activity before diagnosis and risk for death. Fortunately, *if a man engaged in* ***17.5 hours or more of metabolic equivalent activity*** *per week after prostate cancer diagnosis, there was a significant reduction in the likelihood of dying from prostate cancer.* The authors made every attempt to control for possible confounding factors such as reverse causation, meaning that perhaps a man could not exercise as much because of prostate disease.

What does this tell us? Clearly, more and more men who are diagnosed with low-risk disease are choosing active surveillance. They often want to know what they can do that may help them in addition to simply observing their cancer. Vigorous physical activity, to the tune of more than 17 hours of metabolic activity per week, is one practice they can incorporate into their lifestyles, along with a healthy diet. This may help reduce their risk of dying of cardiovascular disease, and, based on these data, it may also reduce their risk of dying from prostate cancer. It is important that physicians convey this information to their patients, particularly those who are on active surveillance. Conclusions from [3]

We found higher levels of postdiagnosis recreational PA were associated with lower prostate cancer–specific mortality (PCSM) . Prediagnosis recreational PA, including walking, was associated with a lower risk of PCSM among men with lower-risk tumors. Given other evidence regarding the beneficial effects of aerobic exercise on reducing fatigue, and improving the quality of life and muscular fitness among prostate cancer survivors our results provide further motivation for prostate cancer survivors to adhere to or exceed recommendations for moderate- to vigorous-intensity activities. This study also supports the importance of ongoing and future clinical trials to assess the influence of PA on tumor progression.

References:

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1. American Cancer Society. ACS Guidelines for Nutrition and Physical Activity. https://www.cancer.org/healthy/eat-healthy-get-active/acs-guidelines-nutrition-physical-activity-cancer-prevention/guidelines.html Accessed September 20, 2017.
2. Haskell WL, Lee IM, Pate RR, et al. Physical activity and public health: updated recommendation for adults from the American College of Sports Medicine and the American Heart Association. Circulation. 2007;116:1081-1093. Abstract
3. Wang Y, Jacobs EJ, Gapstur SM, et al. Recreational physical activity in relation to prostate cancer-specific mortality among men with nonmetastatic prostate cancer. Eur Urol. 2017 Jul 12. [http://www.europeanurology.com/article/S0302-2838(17)30537-7/fulltext

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For Additional Reading go to: http://spendergast.blogspot.com/2017/10/prostatecancer-news-2017-10-october.html

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.

Please help us in our outreach efforts. Our speakers bureau consisting of Lyle LaRosh, Gene Van Vleet and George Johnson are available to speak to organizations of which you might be a member. Contact Gene 619-890-8447 or gene@ipcsg.org to coordinate.

Member and Director, John Tassi is the webmaster of our website and welcomes any suggestions to make our website simple and easy to navigate. Check out the Personal Experiences page and send us your story. Go to: http://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.

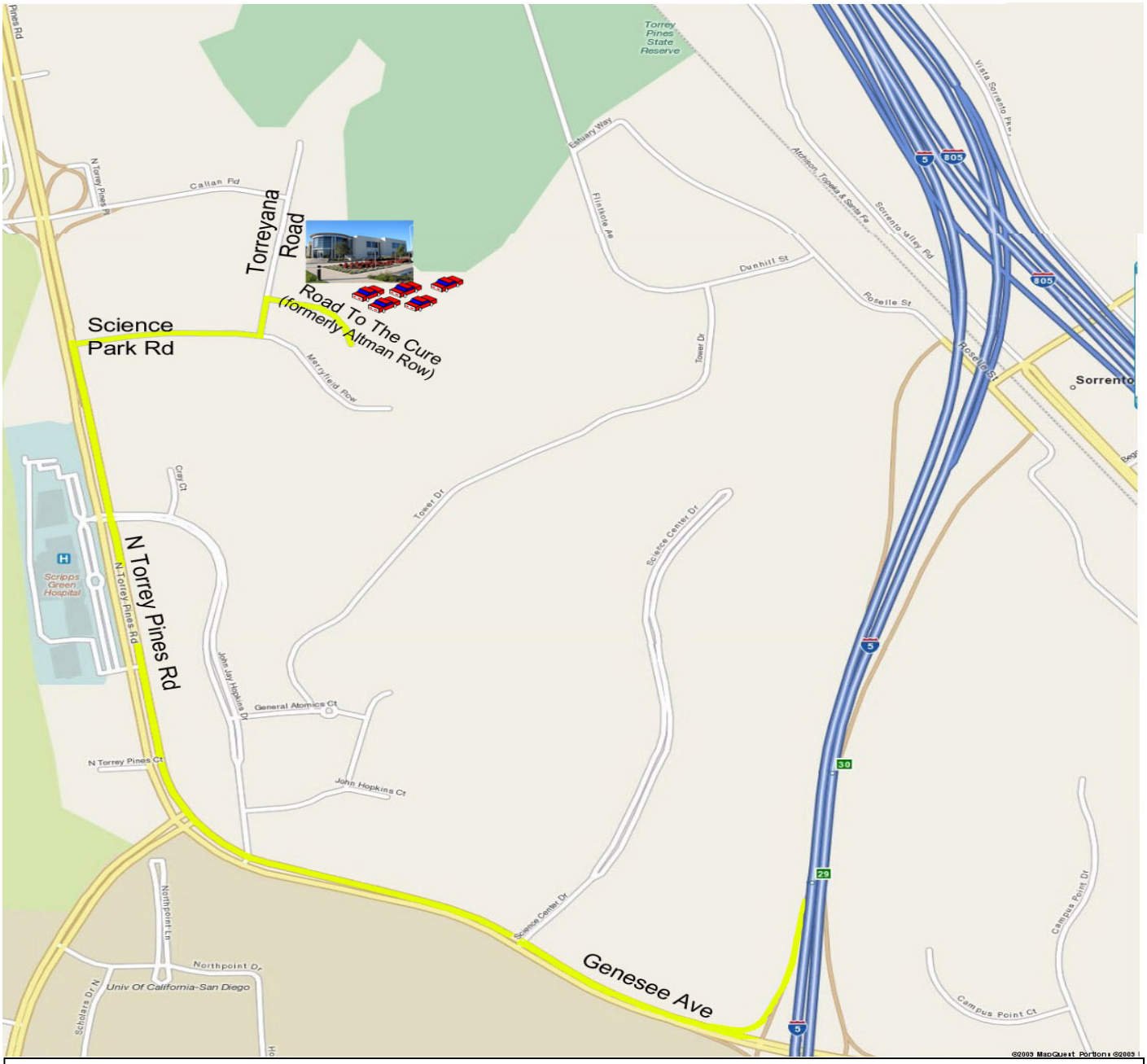
Ads about our Group are in the Union Tribune 2-3 times prior to a meeting. Watch for them.

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-Prebys 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-Prebys Medical Discovery Institute or Fishman Auditorium
Turn right on Science Park Road. Watch for our sign here.
Turn Left on Torreyana Road. Watch for our sign here.
Turn Right on Road to the Cure (formerly Altman Row). Watch for our sign here.