Informed Prostate Cancer Support Group Inc.

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

May 2014 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142

Phone: 619-890-8447 Web: www.ipcsg.org

We Meet Every Third Saturday (except December)

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Editor: Gene Van Vleet

Next Meeting
May 17, 2014
10:00AM to Noon

Meeting at

Sanford-Burnham Auditorium

10905 Road to the Cure, San Diego CA 92121

SEE MAP ON THE LAST PAGE

Wednesday, May 07, 2014 Volume 7 Issue 4

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!!

PROSTATE CANCER IT'S ONLY 2 WORDS, NOT A SENTENCE

April Meeting Recap

Dr. Fabio Almeida, Medical Director of Southwest PET/CT institute and Arizona Molecular Imaging Center presented valuable information about carbon 11 acetate imaging. One area relative to prostate cancer that has not advanced adequately is imaging for recurrent prostate cancer. Dr. Almeida has made significant advances utilizing carbon 11 acetate to detect the location of prostate cancer in patients experiencing recurrence. Recurrence of prostate cancer after treatment is frequent, occurring within 10 years in about 30%-40% of patients. Standard imaging (CT, MRI, Tc Bone Scan) modali-

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://ipcsg.org Click on the 'Purchase DVDs" button.

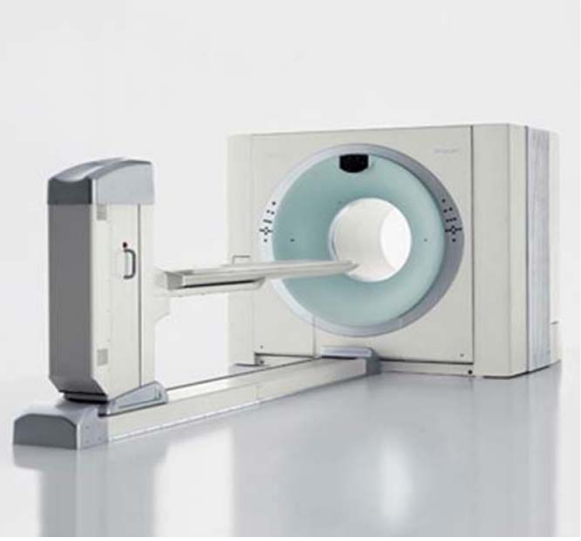
ties are unable to accurately detect local, lymph-node or skeletal metastasis in patients with early bio-chemical recurrence following primary local therapy. Here are comparisons of some techniques now used for this purpose.

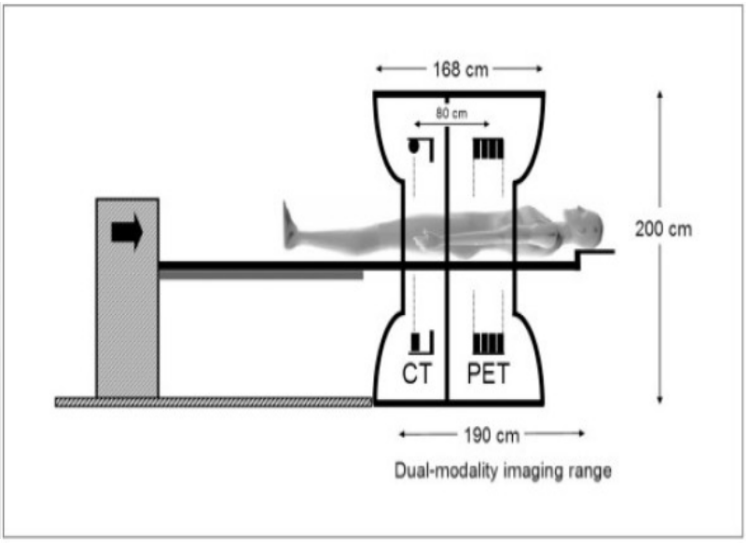
Radiologic Techniques for Identification of Prostate Cancer Metastases

Techniques	Uses	Sensitivity/Specificity
C11-Choline PET/CT	Imaging lipid membrane synthesis via up-regulation of choline kinase. Identifies local recurrences, small nodes and bone lesions. C11 T1/2 = 20 min	Dependent on PSA level. 74% overall detection rate, 86% above 2.0ng/mL. Limited value with PSA <2.0ng/mL. Single site use FDA approval [1] Mild urinary excretion
C11-Acetate PET/CT	Imaging lipid membrane synthesis via up-regulation of fatty acid synthase. Identifies local recurrences, small nodes and bone lesions not identified on other imaging. C11 T1/2 = 20 min	Dependent on PSA level. 87% overall detection rate, 90% above 1.0ng/mL. Performs better than choline at PSA < 3.0ng/mL (77%) [2,3] No urinary excretion
Ga-68 PSMA [Glu-NH-CO-NH-Lys-(Ahx)-[(68)Ga(HBED-CC)](68)Ga-PSMA)] PET/CT	Imaging extracellular PSMA Few small early studies. Uses generator production instead of cyclotron. Ga68 T1/2 = 68 min	60% PSA < 2.0ng/mL 100% PSA > 2.0 Urinary excretion. May miss small lesions in the pelvis.
F18 Choline PET/CT	Similar to C11 Choline F18 T1/2 110 min	Similar to C11 Choline, but extensive urinary excretion. May miss small lesions in the pelvis.
Anti-1-Amino-3-F18-Fluorocyclobutyl-1-Carboxylic Acid (FACBC) PET/CT	Imaging amino acid transport which is up-regulated in PCa. Few small early studies. F18 T1/2 110 min	Too early to tell, but may appear to be better than Choline and may be equal or better to Acetate. Little urinary excretion

1. Mitchell, C. R., V. J. Lowe, et al. (2013). "Operational characteristics of (11)c-choline positron emission tomography/computerized tomography for prostate cancer with biochemical recurrence after initial treatment." *J Urol* 189(4): 1308-1313.
2. Almeida, F. (2011). PET Imaging Characteristics of C11-Acetate in Patients With Recurrent Prostate Carcinoma. *Arizona Molecular Imaging Center*, NCT01304485
3. Almeida, F., Yen, CK., Finkelstein, S. "Early imaging improves performance of C11-Acetate PET/CT for recurrent prostate adenocarcinoma". *UroToday International Journal* – in Press

The carbon 11 acetate imaging utilizes a PET/CT imaging device.





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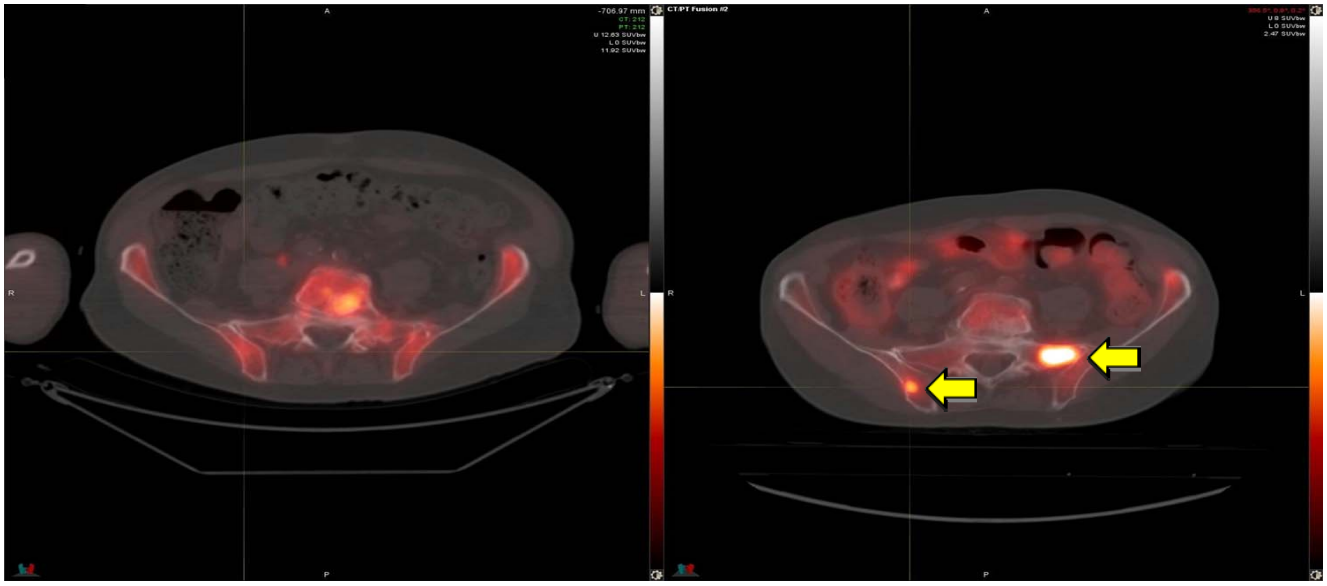
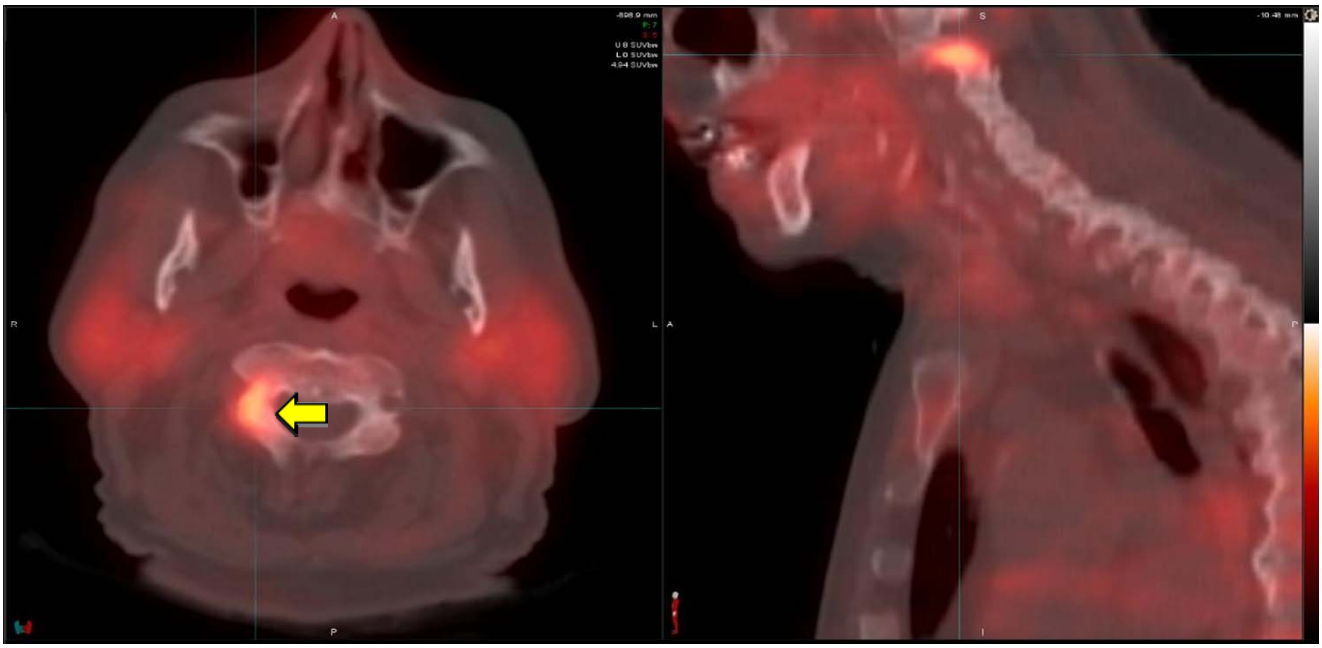
Here are some samples of carbon 11 acetate imaging:



RP 10 years previously (Gs 8, PSA 6.4). Rising PSA = 43.5 ng/mL. F18Na bone scan left compared to C11-Acetate right performed 1 day apart. C11 shows intramedullary pelvic lesions not well seen on F18 scan



Gs 7m PSA 6.1. RP 9 years previously. Rising PSA of 4.8 ng/mL, dT 3.8 months

Single metabolic focus in right C2 pedicle. (SUVmax 5.2). Lesion confirmed on MRI. IMRT performed with follow-up PSA = 0.2 ng/mL.

C11-Acetate PET/CT

Our Experience

> 370 patients (PSA range 0.2 – 148 ng/mL, mean 6.9)

Detection rate (positive C11-Acetate imaging) = 87%

PSA Subgroups

0.2 – 0.4	= 50%
0.41 – 1.0	= 77%
> 1.1	= 90%

Dr. Almeida presented many slides showing the effectiveness of carbon 11 acetate imaging which include patient history of those imaged. For those of you experiencing recurrence, you would be well advised to consider this type of imaging to assist in precisely locating your cancer to assist in making treatment choices. The DVD of this meeting provides much more meaningful detail. Copies will be available at our next meeting on May 17th or through our website: ipcsg.org Click on Purchase DVDs.

FUTURE MEETINGS

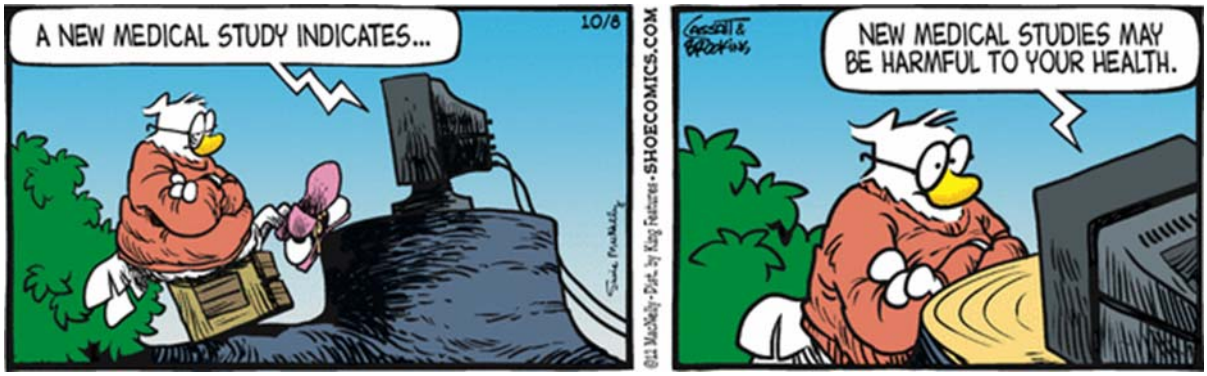
May 17, 2014 - Meeting Agenda: Member Experience Exchange. A selected panel will share their experiences followed by networking among members.

June 21, 2014 - Dr. Irwin Goldstein, Director of Sexual Medicine, Alvarado Hospital speaks about the effects of PCa treatments on sexuality and Dr. Andrew Goldstein updates his work in stem cell research in relation to PCa.

July 19, 2014 - David S. Karow, M.D., Ph.D., Assistant Clinical Professor of Radiology, Director of Body MRI, will be presenting "New imaging innovations in prostate cancer detection and targeted biopsies".

August 16, 2014 - Karen Kunz, Medical Science Liaison, Myriad Genetics. Prolaris Genomic Test as an aid in predicting prostate cancer aggressiveness.

ON THE LIGHTER SIDE



A man walks into his doctor's office and sits down in the waiting room. While he is waiting his turn to be seen, an acquaintance walks in and sits down next to him. The newcomer asks "W w what are yyy you ddd doing here Fred?" The man replies, " I am waiting to see the doctor." "W wwhy dd do yyy you wwant to sss see hhim?" The man replies, "Well, if you must know, I have a prostate problem. " A pp prostate ppp problem, wwhat's ttthat?" "Well, if you must know. I pee like you talk.

For those of you who watch what you eat, here's the final word on nutrition and health. It's a relief to know the truth after all those conflicting nutritional studies:
1. The Japanese eat very little fat and suffer fewer heart attacks than Americans.
2. The Mexicans eat a lot of fat and suffer fewer heart attacks than Americans.
3. The Chinese drink very little red wine and suffer fewer heart attacks than Americans.
4. The Italians drink a lot of red wine and suffer fewer heart attacks than Americans.
5. The Germans drink a lot of beers and eat lots of sausages and fats and suffer fewer heart attacks than Americans.
CONCLUSION Eat and drink what you like. Speaking English is apparently what kills you !

It is OK to keep an open mind as long as you do not let your brain to fall out

How do I know that my youth is all spent?
Well, my get up and go has got up and went.
But in spite of it all I am able to grin
when I recall where my get up has been.

“Right now I’m having amnesia and déjà vu at the same time. I think I’ve forgotten this before.”
— Steven Wright

“Even if you are on the right track, you’ll get run over if you just sit there.” — Will Rogers

As a senior citizen was driving down the freeway, his car phone rang. Answering, he heard his wife's voice urgently warning him, "Herman, I just heard on the news that there's a car going the wrong way on I80. Please be careful!"
"Heck," said Herman, "It's not just one car. It's hundreds of them!"

NOTEWORTHY ARTICLES

Letter from a senior gentleman in Mesa, Arizona:

Dear Family, Friends, Neighbors and former Classmates,

I just found myself in the middle of a medical situation that made it very clear that "the affordable care act" is neither affordable, nor do they care.

I'll go back about seven years ago to a fairly radical prostate surgery that I underwent. The Urologist (a personal friend) who performed the surgery was very concerned that it was cancer, though I wasn't told this until the lab report revealed it was benign. Since that procedure, I have experienced numerous urinary tract infections, UTI's. Since I had never had a "UTI" prior to the prostate surgery, I assume that it is one of the side effects from surgery, an assumption since confirmed by my Family Doctor.

The weekend of March 8-9, I was experiencing all the symptoms of another bout of UTI. By Monday afternoon the infection had hit with full force. Knowing that all I needed was an antibiotic, I went to an Urgent Care Center in Mesa, AZ., to provide a specimen, a requirement for getting the prescription. After waiting 45 min. to see the Doctor, I started getting very nauseous and light headed.

I went to the Receptionist to ask where the bathroom was as I felt that I was going to throw up. I was told that I would have to wait for the Doctor because I would need to leave a specimen and they didn't want me in the bathroom without first seeing him.

That was when the lights went out, my next awareness was that of finding myself on the floor (in the waiting room) having violent dry heaves, and very confused. At this point, I tried to stand up but couldn't make it, and they made it very clear they weren't going to let me get up until the ambulance got there. By the way, when you're waiting to see the Doctor and you pass out, you get very prompt attention.

Now, "the rest of the story", and the reason for sending this to so many of you.

I was taken to the nearest hospital, to emergency. Once there, I was transported to an emergency examination room. Once I had removed my clothes and donned one of those lovely hospital gowns, I finally got to see a Doctor. I asked "what is going on" I'm just having a UTI, just get me the proper medication and let me go home. He told me that my symptoms presented the possibility of sepsis, a potentially deadly migration of toxins, and that they needed to run several tests to determine how far the infection had migrated.

For the next 3 hours I was subjected to several tests, blood draws, EKG's, and demands for specimens. At about 7:30 the nurse came back to my room to inform me that one of the tests takes 1- 2 days to complete, I asked if they (the results) could be emailed, at which point she informed me that I wouldn't need them emailed because I wasn't going anywhere. I started arguing with her but was told, "if you don't start behaving, I'll start taking your temperature rectally, at which point I became a perfect gentleman. I did tell her I wanted to see the doctor because I had no intention of staying overnight.

Now, this is what I want each of you to understand, please read these next sentences carefully. The doctor finally came in to inform me that he was going to admit me. I said, "are you admitting me for treatment or for observation?" He told me that I would be admitted for observation. I said Doctor, correct me if I'm wrong, but if you admit me for observation my Medicare will not pay anything, this due to the affordable care act , he said that's right, it won't. I then grabbed for my bag of clothing and said, then I'm going home. He said you're really too sick to be going home, but I understand your position, this health program is going to hit seniors especially hard.

The doctor then left the room and I started getting dressed, I was just getting ready to put my shoes on when another doctor (the closer) came into the room, he saw me dressed and said, "where do you think you are going?" I simply said "I'm going home, to which he replied, quite vociferously, no you aren't.

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I said, "Doc, you and I both know that under the "affordable care act" anyone on Medicare who is admitted to a hospital for observation will be responsible for the bill, Medicare won't pay a cent". At which point he nodded in affirmation. I said, "You will either admit me for a specific treatment or you won't admit me." Realizing he wasn't going to win this one, he said he would prepare my release papers.

A few minutes later the discharge nurse came to my room to have me sign the necessary papers, relieving them from any responsibility. I told her I wasn't trying to be obstinate, but I wasn't going to be burdened with the full (financial) responsibility for my hospital stay.

After making sure the door was closed, she said, "I don't blame you at all, I would do the same thing." She went on to say, "You wouldn't believe the people who elect to leave for the same reasons, people who are deathly sick, people who have to be wheeled out on a gurney." She further said, "The 'Affordable Care Act' is going to be a disaster for seniors. Yet, if you are in this country illegally, and have no coverage, you will be covered in full."

This is not internet hype folks, this is real, I just experienced it personally. Moving right along, this gets worse.

Today I went to a (required) follow up appointment with my Arizona Family Practitioner. Since my white count was pretty high, the follow up was important. During the visit I shared the experience at emergency, and that I had refused to be admitted. His response was "I don't blame you at all, I would have done the same thing". He went on to say that the colonoscopy and other procedures are probably going to be dropped from coverage for those over 70.

I told him that I had heard that the affordable care act would no longer pay for cancer treatment for those 76 and older, is that true? His understanding is that it is true.

The more I hear, and experience the Affordable Care Act, the more I'm beginning to see that we seniors are nothing more than an inconvenience, and the sooner they can get rid of us the better off they'll be.

November is coming folks, we can have an impact on this debacle by letting everyone in Congress know that their responsibility is to the constituents, not the president and not the lobbyists. We need to let them ALL know that they are in office to serve and to look after the BEST INTERESTS of "we the people", their employers, and not to become self serving bureaucrats who serve only out of greed. And if they don't seem to understand this simple logic, we'll fire them.

On the mend, (signed)

REMEMBER: Demand your hospital admission is for TREATMENT and NOT for OBSERVATION!

Selecting Prostate Cancer Treatment

Posted: 06 May 2014 07:09 PM PDT Prostate Snatchers Blog

BY MARK SCHOLZ, MD

"You mean you have never heard of diffusion-weighted imaging" Exclaimed a recently-diagnosed prostate cancer patient to his doctor. How could his doctor be unacquainted with this important aspect of modern prostate imaging? It's shocking when a patient realizes he possesses more medical information than the "expert."

No One Can Be an Expert in Everything

Actually, in this modern era, this situation is being encountered more and more frequently. It's not so surprising when considering the explosive growth rate of new medical information. It's humanly impossible for anyone to stay abreast of every new medical development. For example, even though urologists

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"specialize" in diseases of the urinary system, their area of responsibility demands expertise in a wide variety of unrelated but important areas such as urinary infections, prostate enlargement, prostate infections, sexual dysfunction and kidney stones. They also have to be expert at the surgical treatment of such problems as congenital defects, bladder cancer, testicular cancer and kidney cancer… just to name a few.

Prostate Cancer by Itself is Quite Complex

Prostate cancer alone is intricate enough to keep a specialist occupied full time. For example, simply staging prostate cancer is complicated. Prostate cancer staging uses a multimodality profiling system that estimatesthe likelihood of microscopic metastases outside the prostate using PSA, Gleason grade, and a percentage of cancer-containing biopsy cores. Now, new imaging techniques are providing further information about the size and location of the cancer within the prostate gland. And even more recently molecular profiling has become commercially available. Staging prostate cancer properly has become a continually developing art form.

Seeking Advice—Delivered from a Level Playing Field

Equally important is the need to seek out unbiased treatment advice. Unfortunately, the process of rendering advice about treatment options is usually very slanted. Urologists (who are surgeons) usually recommend surgery. Radiation therapists usually recommend radiation. This is not to imply that these physicians have less than the best intentions. Over time they just become convinced that what they do is the best option for their patients who are consulting them.

What You Don't Know Can Hurt You

The number of treatments available for men with newly-diagnosed disease is rapidly expanding. For example, what was previously known simply as "radiation" now includes IMRT, Proton therapy, Cyberknife, two types of Brachytherapy as well as various combinations of these different radiation modalities. Hormone therapy options have now expanded beyond traditional Casodex and Lupron to include Zytiga and Xtandi. The management of the potential side effects of hormone therapy requires special training in diet physical fitness, bone integrity and sexual health to limit the risk of lingering damage after treatment is completed. These days, relapsed or advanced prostate cancer requires physicians who are conversant in genetic typing, modern PET scans, immunotherapy and injectable radiation.

Every Journey Begins with a Single Step

So newly diagnosed prostate cancer patients are faced with daunting situation. Clearly there is no simple answer to this tangle of complicated issues. However, the newly diagnosed cancer patient is far from helpless. He has two overriding responsibilities. First, he must learn as many facts as possible by getting thoroughly educated about the different treatments for his specific type of prostate cancer. Second, he must use discernment in the selection of which physicians to consult.

There is Time to Learn

With prostate cancer there is rarely a need to rush into making a treatment decision because it is usually slow growing. There is plenty of time for the shock of diagnosis to wear off, giving you enough time to get educated about the scientific facts. Published studies comparing outcomes are available. The PCRI in particular publishes articles that translate scientific information into a patient-friendly format. Ultimately, all claims about treatment should be supported by references published in the scientific literature. Selecting treatment for prostate cancer is a high stakes proposition, potentially risking sexual function, urinary function, even life itself. I want to encourage patients to take a leadership role in the treatment-selection process.

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New method for prostate cancer detection can save millions of men painful examination

From Science Daily, April 7, 2014

Hundreds of thousands of men die each year from prostate cancer. The standard procedure used worldwide for prostate cancer examinations starts with measurement of the PSA (prostate specific antigen) value in the blood. If this is high, physicians will usually remove samples of prostate tissue through the anus at six to sixteen points for pathological examination. However, 70% of the subjects show no signs of cancer. So does this mean the high PSA level is a false alarm? Not always: the biopsies may have been taken at just the wrong places. Cancer is later found in 30% of the patients with negative results (no cancer). Among the positive results (patients with signs of cancer), doctors do not know the exact sizes of the tumor. In many cases, operations show that the tumors are so small that surgery was unnecessary. As well as that, the examination leads to inflammations in up to 5% of patients. Plus the fact that each examination costs around USD 2500 to carry out.

Recognizable blood vessel pattern in cancer

Research team leader Massimo Mischi at TU/e has developed a method to investigate whether and where men have prostate cancer using existing ultrasound scanners, together with the Academic Medical Center Amsterdam. These devices create images of organs in the body using sound waves, in the same way as prenatal ultrasound scans. But these systems are usually unable to show the difference between healthy and tumor tissue. To make this visible, Mischi used the fact that tumor tissue produces large numbers of small blood vessels to allow it to grow, with a characteristic pattern. Patients are given a single injection of a contrast medium containing tiny bubbles, which are shown by the ultrasound scanner right down to the smallest blood vessels. Using advanced image-analysis techniques that can recognize the characteristic blood vessel pattern in tumors, the computer then generates an image showing where the tumor is. The examination only takes one minute, and the results are available no more than a few minutes later. These examinations also save money, because costly biopsy analysis is no longer necessary.

Precise prediction

The researchers were able to compare the 'tumor images' from 24 patients at three hospitals in the Netherlands with the actual prostates after removal by operation. The images were found to give a good indication of the locations and sizes of the tumors. Massimo Mischi will present the results at the European Association of Urologists Congress in Stockholm on 14 April. It is exceptional for a scientist from a university of technology to be given the opportunity to speak at this congress of medical specialists.

Far fewer biopsies

The use of the new method, which has been patented by TU/e, can avoid the need for biopsies to be taken from millions of men around the world. The procedure will no longer be necessary for a large part of the 70% of men from whom biopsies are currently taken unnecessarily. And far fewer biopsies will need to be taken from the remaining 30% because the location of the tumor is already clear. Once the new method has been sufficiently proven in clinical practice, the need to do biopsies may even be eliminated almost entirely.

Quick and simple introduction

The research is being carried out together with the Academic Medical Center Amsterdam and two other Dutch hospitals. A major comparative study will be held in these hospitals next year between the old and new methods, to proof that the new method is better. This will involve the use of both methods on at least 250 men. If all goes well the method will also be made available from 2016 for other patients, a large part of which will then no longer have to undergo the old and painful form of examination. The new method can be introduced quite simply because no new equipment is required; the existing ultrasound scanners which the hospitals already have can continue to be used.

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 times prior to a meeting. Watch for them

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.

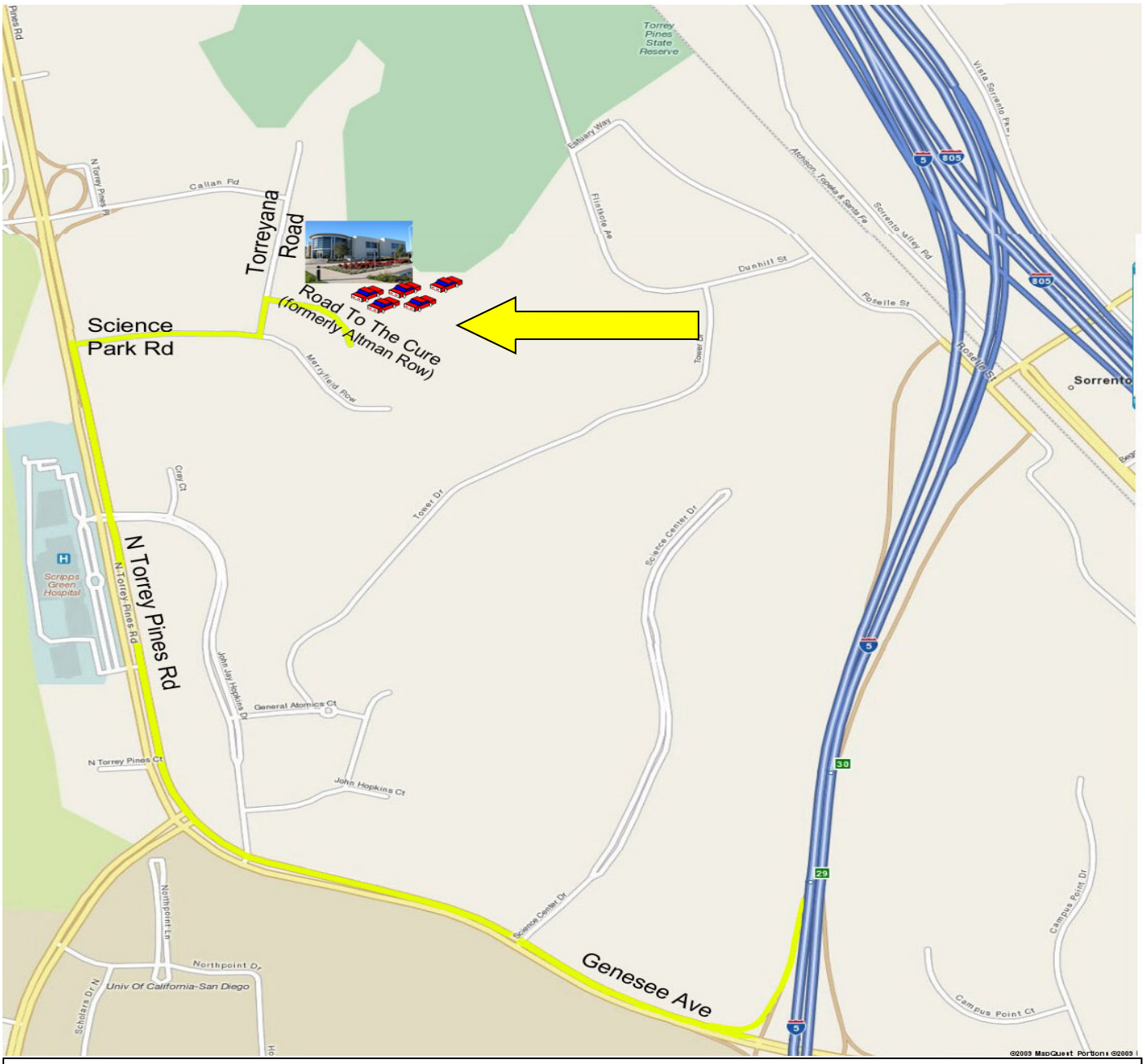
Anyone interested please contact: Gene Van Vleet, Chief Operating Officer. 619-890-8447 gene@ipcsg.org orLyle LaRosh, President 619-892-3888 lyle@ipcsg.org

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).