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

APRIL 2018 NEWSLETTER

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

We Meet Every Third Saturday (except December)

Sunday, April 15, 2018

Volume 11 Issue 4

Next Meeting
April 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

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.

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Editor: Stephen Pendergast

PROSTATE CANCER IT'S ONLY 2 WORDS NOT A SENTENCE

George Johnson – Successful Living with Prostate Cancer

March 2018 IPCSG Meeting Summary by Bill Lewis.

In contrast with IPCSG meetings about various treatments for Prostate Cancer (PCa), this meeting focused on how to deal and cope with those PCa treatments, to extend our useful activities. George presented 5 Keys to Success, and solicited member views and experiences

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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" tab.

The DVD of each meeting is available by the next meeting date.

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on each, in a group sharing discussion. The information presented to start the discussions was derived from George's study of information from Harvard Medical School, the Mayo Clinic, the McArthur Foundation, and the UCSD Center for Healthy Aging.

Kaplan-Meyers graphs are plots of "days to death" for various populations with cancer or other diseases. A line can be drawn showing the median number of days to death, representing days elapsed when half of the population studied has died. It's common for a person to focus on this number of days (or months or years) and begin to think, "I'll likely be dead by that time" – and become depressed. However, these plots always have a long tail, representing a certain proportion of the persons living much longer – even several multiples of the time to death for the first half of the population. These curves have also been worked out as "Life Expectancy," even for the general population. The upshot is that half the men who reach their 40's will have died by age 82. Ditto for 50-year-olds. Half of those reaching their 60's are expected to die by age 83. Likewise, reaching one's 70's gives a little more expected life, to 85. Half of those reaching their 80's will be expected to pass on by 89. And reaching 90 only gives 4 more years of life expectancy.

How do you beat these odds? How do you get on the right side of the graph (beyond the median time to death), where the long tail of survival is?

Men with prostate cancer have shorter life expectancies than the general population, particularly depending on their Gleason score. But George, for example, has very aggressive PCa, with a Gleason score of 9. He has lived with it for 20 years, and is now 85. Even his doctor asked what he was doing right. However, his PSA began rising again recently, and he is just starting to take Zytiga. He also just had some skin cancer removed. You can get more than one cancer.

In general, men with PCa are under special stresses: Anxiety about longevity, Confusion about treatment selection and efficacy, Concern about disease recurrence and progression, Impacts of difficult side effects. They also face the common male aging concerns: Declines in vitality, Low libido, Depression, etc.

What are side effects of PCa and various treatments? Bone loss, Muscle loss, Memory loss, Libido loss, Weight loss or Weight gain, Fatigue, Anxiety, Depression, Hot Flashes, Breast growth, Incontinence, Anger, Constipation, and more.

What can be done? There are 5 Keys. For each, he gives a "statement" and a comment on the "value" of the key.

Key #1 – DIET (relevant PCa side effects: weight gain or loss, appetite loss, taste loss)

Statement: The PCRI (see pcri.org) warns, "Most of you men will die of heart disease." Value: Dr. Mark Moyad states, "Whether or not any diet or supplements could improve your PCa prognosis specifically has not been proven, but a man who eats a moderately healthy diet and maintains a healthy weight may reduce his risk of other diseases that can reduce his life expectancy." Sharing: Bill Manning shared his experience with 9 years of a vegan diet. He noted that there are plenty of types of plant-derived protein out there, and many books available for recipes. The China Study book gives the rationale for a plant-based diet. He described a simple recipe for a crockpot stew/chili that even his anti-vegan relatives love: black beans, red beans, sautéed onions and garlic, diced tomatoes, fake ground-beef crumbles, seasoning (including lots of chili powder). The recipe came from a Vegan Slow Cooker book on Amazon (a glance there will show a dozen similar books). Great as-is (fresh or frozen-then-thawed-later) or over a baked potato. Gene Van Vleet shared that his diet is "eat less." Eliminating meat and milk, and following Mediterranean diet principles helped him lose weight. George recommended the "Half Diet." He eats half what he used to, though still typical Minnesota foods. You can eat half of what's on your plate, or eat half as fast (then stop), or only put half as much on your plate to start.

Diet suggestions: a balanced diet, a heart-healthy diet, an Asian diet (fish, tea, soy, brown rice), Mediterranean diet (tomatoes, fish, olive oil, & whole grains (for fiber)), Vegan Diet, and Anti-oxidants (spinach, broccoli, blueberries, etc.).

Avoid: Red meat and dairy products (see the China Study book), Alcohol (except a single 5-ounce glass of wine; heavy drinkers have 2-3X the rate of prostate cancer), Folic acid from pills and Mega-dosing with vitamins, etc.

A question: what about sugar? George recommends avoiding sugar and simple carbohydrates (eg, white bread)

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because without fiber to slow down absorption, the blood insulin level rises – which is bad for you if you have cancer. Fiber is good, but fiber pills are not – you have to take half a bottle to have an effect.

Key #2 – EXERCISE (PCa side effects: muscle loss, bone loss, weight gain, heart effects, fatigue and depression)

Statement: "Walking is a man's best medicine (Hippocrates)." If brisk, it will cut strokes by 40%. Value: Reduced prostate/colon/breast cancer, improved blood flow, reduced diabetes and lower blood pressure. Essential if on ADT!

Gene Van Vleet shared that his serious exercise program (an hour a day at the gym -- cardiac and stress exercises, six days a week) reduces side effects of his medications, and has eliminated the need for him to take blood pressure medication. Get a trainer and get going. With diet and exercise, he reduced from 240 to his target 205 lbs. Stephen Pendergast had done exercise prior to surgery to prepare, and is back at it. He prefers swimming because of less stress on several bone-related health problems he has had long-term. When he went on ADT, he had to add weight training three times a week to slow down muscle loss and minimize weight gain. Ron Abbott noted that it helps him to have a partner, to go to the gym with.

Suggestions: Aerobic, strength, stretching, Walking, Swimming, … Thinking? … No, action is needed! Avoid: "The Couch."

Key #3 – SOCIALIZATION (PCa side effects: loneliness, isolation, depression, anxiety)

Statement: "The leading cause of mortality for elders is … loneliness! Especially for men – 3X mortality. Value: Boost in immune systems, lower blood pressure, reduced stress, increased laughter (such as in the group that meets after this support group each month, at the local Bristol Farms market). Note: Chronic stress doubles the risk of Alzheimer's disease.

Suggestions: "Get out of the house!" "Get out of yourself." Maintain close relationships, don't withdraw. Broadcast how well you feel and how successful your surgery/treatment has been, to counteract the assumption of most people that "Cancer means death." Get involved in activities that are meaningful and purposeful, like service work – continuous group engagements are best. Discover and rediscover relationships, send <u>regular</u> emails, make <u>brief</u> phone calls, join garden and book clubs. Volunteer in civic, spiritual, medical, educational or environmental activities. Check the local website, volunteermatch.org (see also justserve.org or google "community service san diego").

Avoid: Daytime TV; CNN at night – which is "Breaking Bad News." Don't say "I'm just a retired person."

"To run fast – go alone. To run far – go with others (a saying from Kenya, Africa where the great runners are).

Key #4 – INTELLECTUAL (PCa side effects: memory loss, depression, fatigue)

Statements: Brain health is a growing science. There is a great need to exercise your brain. "Use it or lose it." Challenge it. Learn new things. Value: Reduce memory loss, opens new interests & horizons, enjoy refreshing and stimulating activity. Sharing: Stephen Pendergast researches new findings about PCa on the internet, and puts key items into the newsletter, which he was "encouraged" to take over the editorship of. Also learns from five years of attending our meetings. Another member repairs radios of all types/vintages. Another plays games, especially puzzles and ones with plot lines. Another is happy to be back at work after a 9-week hiatus after surgery. A taxi driver plays chess with his associates during his break times. Mira Costa college has two lecture series going each week. Bill Bailey plays a lot of online chess, and meets people all over the world. Toastmasters is a lot of fun and great stimulation for the mind. There are over 40 clubs in the San Diego area. He tutors neighbors in computer skills, and there's a lot of demand.

Suggestions: Use your gifts, business skills, tutoring capabilities. Activate the right brain, the creative side, challenge yourself, your artistic self. Energize it. George Johnson took up painting. Talking is a stimulus if it is a subject discussion or an exchange of ideas, beyond just a general social discussion. Other stimulating activities – Take classes, piano lessons, dance lessons; Learn a new language or skill; Join a Support Group; Bridge, crosswords puzzles, reading, etc. Check out this website – www.lumosity.com/mental-training AVOID: Politics & home-owners associations!

Is there another key? The McArthur Foundation Study on Successful Aging – "Physical fitness is just one of many

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important factors. We were surprised to learn [1984] mental abilities and social relationships were also critical." Buried in the report were two other studies on the impact of positive and negative training on outcomes: "Helplessness and Depression" by M.Seligman, 1975. Tells about learned helplessness. "Self-efficacy" by A. Bandura, 1997. Self-efficacy – "The Can Do Attitude (Spirit)" is known as a major difference in health recovery …..alone or with others?

Key #5 – SPIRITUALITY Definition: Belief in a Higher Power or Creator.

Health Effects: Studies have reported a positive correlation between spirituality and mental well-being in both healthy people and those encountering a range of physical illnesses or psychological disorders.

Spiritual individuals tend to be optimistic, report greater social support, and experience higher intrinsic meaning in life, strength, and inner peace. – UCSD Health Center.

PCa Side Effects – All those listed above are relevant.

"Wow, as a scientist the data show something is going on here." -- Dr. R. Hummer, University of Texas: a 7-year increase in life span, 25% lower mortality, and 65% lower markers for cardiovascular disease.

Value statement: Spirituality gives a higher degree of optimism; adverse events are viewed as temporary; promotes a concern for others and a higher sense of well-being & "peace of mind. By invitation, Bill Lewis commented on the support that prayer has been to him through family, friends, and a church prayer roll, and confirmed that his spiritual activities give him a greater sense of peace, of purpose in life and closeness to God. He noted he often gets comments that he has never looked as healthy as he does now, despite battling stage 4 prostate cancer. George commented on "The Book of Joy" by the Dalai Lama and Desmond Tutu, which asserts that helping others, thinking of others, participating with groups, getting outside of yourself and having a positive viewpoint in life can really have a major impact on your health and your outlook.

SUGGESTIONS: Prayer, Meditation, Daily reflections and study guides, Regular attendance to churches, synagogues, or mosques, Active service & visitations (George has had good experiences visiting Alzheimers patients, who love to talk about their childhood, being on the farm, etc. – wonderful stories), Make a gratitude list when you are moping around.

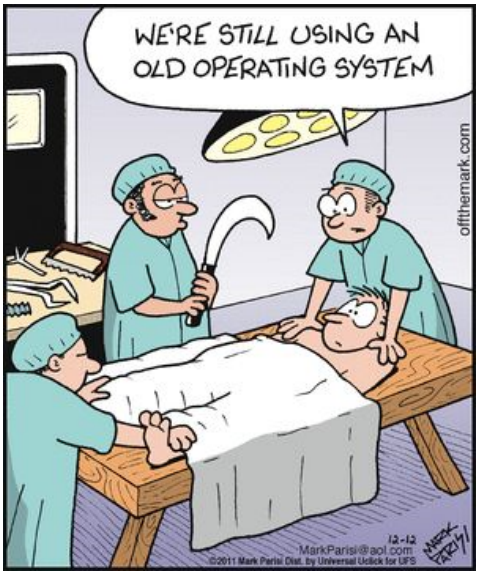
"The results underscore the health implications of social connections and positive mental stimulus." Stephen Pendergast commented that his church, like many others, carries the social aspect into spirituality through many group and social activities. The LiveStrong program at several YMCA's in the area was recommended by a member. It's a free 10-week personal training program for cancer survivors, including Yoga and nutrition, that can be followed by a free membership with half-price monthly fees for the whole family.

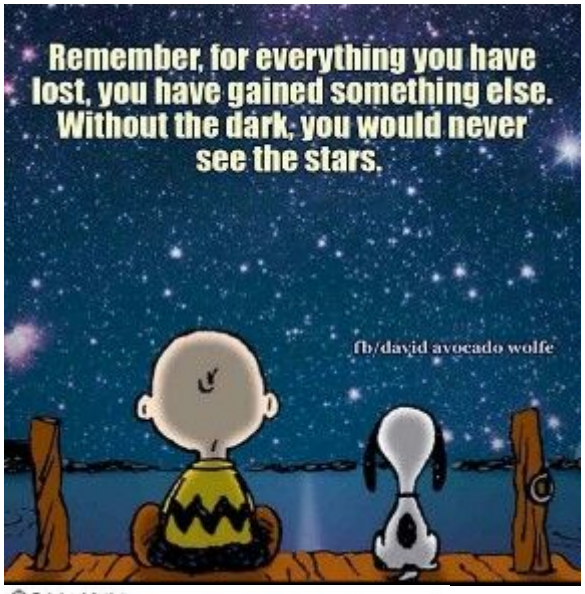
A Can-do Spirit: I will go forth with God into this day with enthusiasm, believing in my own value and worthiness, and with the determination to enjoy this day and give it my positive best.

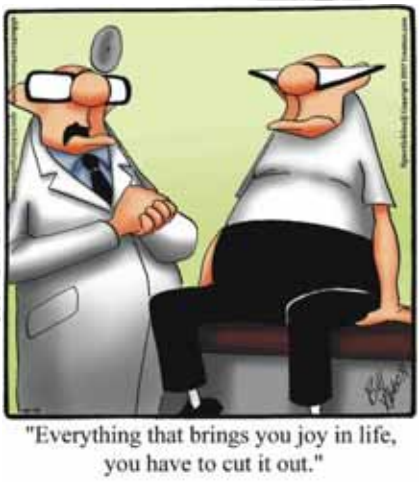
Breakout sessions were then held, for individual questions/discussion regarding Surgery, ADT & Hormones, Radiation, Active Surveillance, and Newcomers.

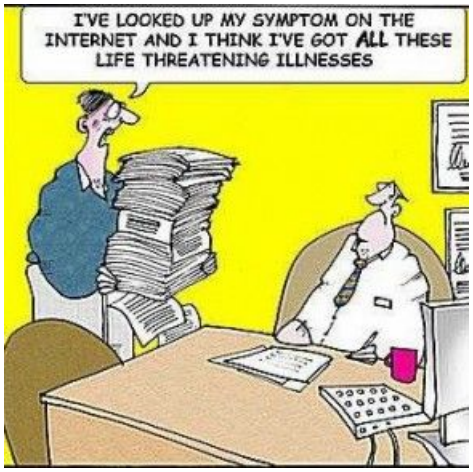
A video of the March IPCSG meeting, including the slides, will be available via the website shortly before the next meeting, or at the April meeting on the 21st.

ON THE LIGHTER SIDE









FUTURE MEETINGS

- Meeting Date SPEAKERS
- April 21 Dr. Paul Dato - Decision Factors
- May 19 Dr Schwartzberg - Nanoknife

- **For further reading:**
  http://spendergast.blogspot.com/2018/03/prostatecancernews-2018-03.html
- **For Comments, Ideas and Questions,**
  email to Newsletter@ipcsg.org

INTERESTING ARTICLES

www.medscape.com

Comparative Toxicities, Cost of 3 RTs for Prostate Cancer

Pam Harrison
March 29, 2018

A new study compares outcomes among younger men with prostate cancer who are treated with *intensity-modulated radiotherapy (IMRT),* which is the most commonly used form of radiotherapy (RT) in the United States, against outcomes with two less frequently used technologies, *proton therapy* and *stereotactic body radiotherapy (SBRT)*.

The investigators report that men treated with proton radiation are less likely to experience adverse urinary effects and erectile dysfunction and more likely to have bowel toxicity at 2 years compared with men treated with IMRT.

The study also reports on cost. Proton therapy was nearly twice as expensive as IMRT, based on private insurance reimbursement costs.

In contrast, the costs of administering SBRT and IMRT did not significantly differ, although SBRT treatment is associated with a modestly higher risk for urinary toxicity than IMRT.

"[T]o our knowledge, this study is unique in its assessment of the toxicity and cost of prostate radiation treatment options in the previously understudied but significant patient population of younger men with private insurance," Hubert Pan, MD, the University of Texas MD Anderson Cancer Center, Houston, and colleagues write.

Men under age 65 years account for over 40% of all patients with prostate cancer.

"[Our] key findings, coupled with the real-world private insurance cost…will be useful for patients selecting the most appropriate treatment and for researchers designing cost-effectiveness models to guide treatment decisions in prostate cancer," the authors add.

The study was published online March 21 in the *Journal of Clinical Oncology*.

Using a large US commercial insurance database of men under age 65, the investigators matched 693 patients who had been treated with proton therapy to 3465 patients who had been treated with IMRT. Another 310 men treated with SBRT were matched to 3100 others treated with IMRT.

Median follow-up for all groups ranged from 18 to 23 months.

One third of men who underwent proton radiotherapy experienced some form of urinary toxicity at 2 years compared with 42% of those who received IMRT ($P < .001$).

"This urinary benefit with proton radiation was seen across multiple domains, including incontinence, bleed-

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ing/irritation, obstruction, and stricture," the study authors note.

On the other hand, 20% of men who received proton therapy had some form of bowel toxicity at 2 years compared with 15% of IMRT patients (*P* = .02) — principally in the form of late bleeding or proctitis.

Erectile dysfunction was also less common among men who received proton treatment, at 21% at 2 years vs 28% for those treated with IMRT (*P* < .001).

The mean cost of administering proton radiation to the payer was $115,501 compared with only $59,012 to administer IMRT (*P* < .001).

For patients, out-of pocket costs were also higher for men receiving proton therapy, at $2269 compared with $1714 for men receiving IMRT (*P* < .001).

Not surprisingly, the cost of treating complications was lower for patients receiving proton therapy, at a mean of $1737 at 2 years compared with $2730 with IMRT (*P* = .008).

However, mean total healthcare costs at 2 years were higher with proton radiotherapy, at $133,220, than with IMRT, at $79,209 (*P* < .001).

As the investigators observe, the higher cost of using proton radiation to treat patients with prostate cancer reflects the fact that private insurance companies spend nearly twice as much on proton radiation treatment as they do on IMRT.

SBRT vs IMRT

A comparison of toxicities associated with SBRT vs those caused by IMRT revealed no differences in composite rates of urinary, bowel, or erectile dysfunction toxicities between the two modalities.

However, obstruction and retention rates at 2 years were higher with SBRT than IMRT, at 21% and 15%, respectively (*P* = .003), as were fistula rates, at 1% vs 0.1% (*P* = .009).

The mean cost to the payer of treating men with SBRT was actually lower than it was for IMRT, at $49,504 vs $57,244, respectively (*P* < .001).

For patients, the mean out-of-pocket costs — $1015 for receiving SBRT vs $1560 for IMRT — were relatively similar, but the difference between the two treatment modalities was still significant (*P* < .001).

In contrast, the mean cost of treating complications and total healthcare costs were similar between SBRT and IMRT and were not significantly different at 2 years.

"To our knowledge, this study is the first to identify possible benefit associated with proton radiation compared with IMRT for prostate cancer, with results suggesting decreased multidomain urinary toxicity," study authors write.

"[But] with the current emphasis on cost-effective health care, our toxicity findings must be considered in the context of differing cost profiles," they add.

The study was supported by the Cancer Prevention and Research Institute of Texas, the National Cancer Institute and Varian Medical Systems. Pan reports receiving research funding from Varian Medical Systems.

J Clin Oncol. Published online March 21, 2108. Abstract

For more from Medscape Oncology, follow us on Twitter: @MedscapeOnc

Cite this article: Comparative Toxicities, Cost of 3 RTs for Prostate Cancer - *Medscape* - Mar 29, 2018.

Food Boosts Impact, Lowers Cost - Savings Per Patient As High As $300,000

UNIVERSITY OF CHICAGO MEDICAL CENTER

By taking a high-cost drug with a low-fat meal--instead of on an empty stomach, as prescribed--prostate cancer patients could decrease their daily dose, prevent digestive issues and cut costs by 75 percent, according to a new study in the March 28,2018, issue of the journal of Clinical Oncology (CO). Abiraterone acetate, marketed as Zytiga®, is the standard medicine used to treat metastatic castration-resistant prostate cancer. Patients taking Zyti-

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ga are told to take four of the 250 milligram pills first thing in the morning. Then, having gone without food overnight, they must wait at least one more hour before eating breakfast. "This schedule is not only inconvenient for patients, it's also wasteful, in several ways," said the study's lead author, Russell Szmulewitz, MD, associate professor of medicine at the University of Chicago and a prostate cancer specialist.

A one-month supply of the recommended dose of abiraterone costs $8,000 to $11,000 when purchased wholesale. That adds up to a little more than $100,000 each year. Many patients take the drug for two to three years. So Szmulewitz and colleague Mark Rata in, MD, the Leon 0. Jacobson professor of medicine and director of the Center for Personalized Therapeutics at the University of Chicago Medicine, designed a randomized clinical trial to see if the drug could be used more efficiently and at less expense.

Abiraterone, approved in 2011 for the treatment of metastatic prostate cancer, has a "food effect" that is greater than any other marketed drug. The amount of abiraterone that gets absorbed and enters the blood stream can be multiplied four or five times if the drug is swallowed with a low-fat meal (7 percent fat, about 300 calories). That can increase to 10 times with a high-fat meal (57 percent fat, 825 calories).

Working with colleagues at the University of Chicago as well as researchers at the National Cancer Institute, Emory University, Illinois Cancer Care in Peoria, Illinois, and the National University Cancer Institut e, Singapore, the team designed a clinical trial that could compare the cost, risks and benefits of taking this drug with or without breakfast. The study launched in 2012. The team enrolled 72 patients with advanced prostate cancer.

Half of those patients agreed to take the recommended dose of 1,000 milligrams: four pills each morning with water on an empty stomach. They had to wait an hour afterwards before they could eat breakfast. The other half were told to take one-fourth of the standard dose, a single 250-milligram pill, with a low-fat breakfast such as cereal with skim milk. Patients were advised to avoid high-fat items such as bacon or sausage. Four patients, two from each group, dropped out before the study began.

The researchers found that the lower dose with breakfast kept the disease under control as well as the recommended dose. Abiraterone's ability to lower levels of prostate-specific antigen, a surrogate marker for prostate cancer, was slightly greater for patients in the low-dose with food group when measured at 12 weeks.

Progression-free survival for patients in both the low- and high-dose groups was identical, about 8.6 months. Despite the small size of the study, the authors were confident that the low-dose arm was comparable to the standard dose. It was also slightly more convenient and much less expensive, cutting costs by as much as $300,000 per patient.

"The patient gets a simplified schedule, slightly more control over his daily life, the convenience of eating whenever he chooses and the opportunity to share the cost-savings with his insurance company," Szmulewitz said. "Taking this medicine while fasting is wasteful." "Although it should be validated with a larger trial with more robust clinical endpoints," he added, "given the pharmacoeconomic implications, these data warrant consideration by prescribers, payers and patients." "

If this study were enlarged and repeated successfully**, the resulting cost saving would be in the billions of dollars,**" according to Allen Lichter, MD, author of a related commentary in the JCO, former CEO of the American Society of Clinical Oncology and board chair of the Value in Cancer Care Consortium (Vi3C).

Abiraterone, taken with prednisone to prevent side effects, "represents a new standard of care for metastatic disease," according to a recent review article in the New England journal of Medicine. The authors were concerned, however, that the "duration and cost of treatment may influence clinical decision making." At a per-patient cost of about $10,000 a month, "this is a textbook example of what we now call 'financial toxicity'," Rata in said, referring to the economic burden placed on patients by the high cost of care. "At least three-quarters of this expensive drug is wasted," he added. "It's excreted and flushed away."

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Additional authors of the study were Abiola Ibraheem, Elia Martinez, Mark Kozloff, Chadi Nabhan, Theodore Karrison and Walter Stadler from the University of Chicago; Cody Peer and William Figg from the National Cancer Institute; Bradley Carthon and Donald Harvey from Emory University; Paul Fishkin from Illinois Cancer Care, in Peoria; and Wei Peng Yong and Edmund Chiong from the National University Cancer Institute, Singapore.

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.

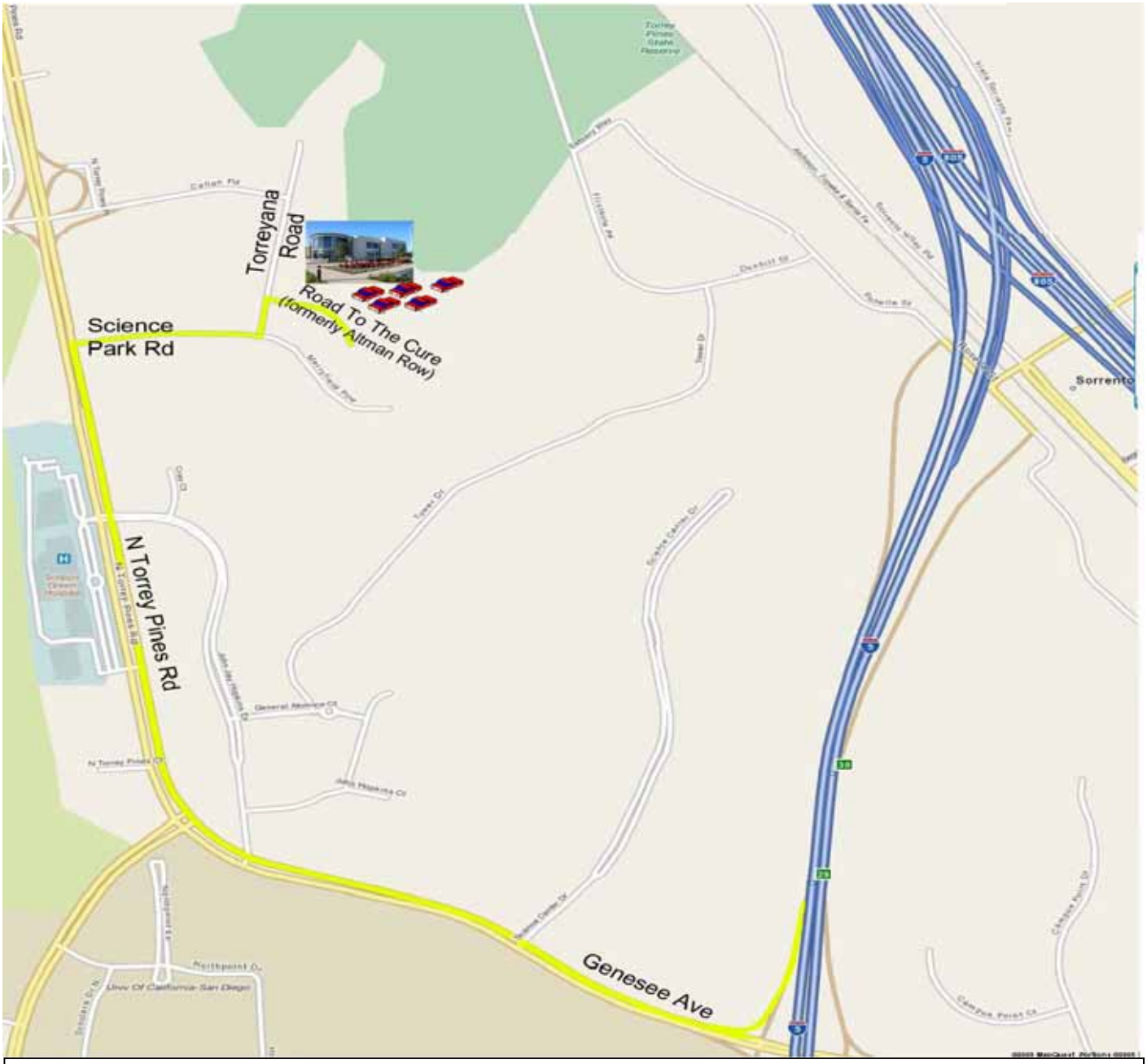
Ads about our Group are in the Union Tribune 2 times prior to a meeting. Watch for them.

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.