



**LYLE LAROSH
RECEIVES
PRESTIGIOUS
PCRI HARRY
PINCHOT
AWARD!!!!**
(See story below)

Informed Prostate Cancer Support Group, Inc.

P.O. Box 7033 San Diego, CA 92167



SEPTEMBER 2009 NEWSLETTER

Board of Directors

- President:** Lyle La Rosh, (619) 892-3888
Vice President Victor Reed, (619) 479-3720
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Director Gene Van Vleet (619) 316-3354
Director Bill Geideck

Steering Committee

- Bob Coates
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**Next Meeting is Sep-
tember 19, 2009
10:00AM to 12:00PM**

**John Moore's
Cancer Center,
UCSD
3855 Health
Sciences Dr.
La Jolla Ca 92037**

**(NOTE: Free Parking
is in lots P703 & P704
(See Map on page #5).**

Sunday, September 13, 2009

Volume 2, Issue 9

What We Are About

Our Group is a Source of Information for a High Quality of Life. We urge you to call one of our group leaders BEFORE making any treatment decisions. We frequently learn that men who are newly diagnosed with PC are overwhelmed by the frightening magnitude of their condition. They opt for immediate resolution of their disease, which usually ends up with surgery, radiation, or other invasive treatment.

Our experience tells us that PC is usually a slow growing disease which can often be controlled by other means. Hence, we advocate getting a second opinion, preferably from an Oncologist who specializes in PC. This is why we recommend talking to our members, most of whom have already been through the decisions you're confronting.

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The Prostate Cancer Research Institute (PCRI) awarded its annual Harry Pinchot Award to IPCSG President Lyle LaRosh.

This award honors lay persons who show excellence in prostate cancer education, research, advocacy and community support. How well this describes what Lyle is and does!

Through self-study, research and interfacing with medical professionals, Lyle has become one of the most knowledgeable lay persons in prostate cancer diagnoses, types of treat-

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THE FOLLOWING VIDEO DVDS ARE FOR SALE AT THE IPCSG LIBRARY FOR A DONATION OF \$10.00:

- Dr. Duke Bahn
 Dr. Susan Foley
 Dr. Mimi Guarneri
 Dr. Irwin Goldstein
 Dr. Richard Lam
 Dr. Juergen Winkler
 Dr. Susan Foley-Feb Mtg
 Dr. Christopher Kane-Mar Mtg
 Dr. Hugh Smith-Apr Mtg
 Dr. Richard Safrin-Jul Mtg
 Dr. Richard Lam-Aug Mtg**

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ments, side effects, quality of life and impact on families. His breadth of knowledge and the ability to impart that to others is extraordinary and highly respected by the medical community. All of us have benefited from his unassuming demeanor and single-minded purpose to help us with deal with our disease. Through his leadership we have become one of the largest independently organized and financed support groups. Through this award will come even more recognition for what we do.

Congratulations to Lyle and to IPCSG for what he is and thus we are!

August Meeting Notes



Our guest speaker was Dr. Richard Lam of Prostate Oncology Specialists. He opened with a discussion of the PSA screening debate that was brought to the forefront by a European screening trial of 162,000 men. In the screening group, PSA was tested every 4 years and action was taken if PSA was greater than 3.0. The control group had no PSA testing. The result was that only 1 man was saved per 1,410. He then presented the advantages and disadvantages of the various methods of treatment including radical prostatectomy, cryosurgery, external beam radiation and active surveillance. Active surveillance is distinguished from watchful waiting in that it is intended to treat when the time is right. He discussed ultrasound as an additional method to monitor the prostate situation. This exam can be utilized to identify favorable/non-favorable lesions and can measure tumor progression objectively. He then discussed systemic therapies that are important for high risk localized disease and relapsed disease. These therapies include hormone therapy, chemotherapy and immunotherapy. Promising treatments for hormonal refractory disease include abiraterone, MDV3100 and taxotere-based regimens. Promising immunotherapy based therapies include GM-CSF, Provenge, Pox vaccines and ipilimumab.

For details of Dr. Lam's presentation, DVD's are available for purchase in the IPCSG library.

Special Announcement—Parking

Only lots P703 and P704 as shown on the map on page 5 are free on the week-end. Paid parking nearer to the meeting place is in lot P764 (HANDICAPPED ARE FREE). There have been complaints about difficulty operating the pay device in this lots. Gene Van Vleet has had further discussion with authorities regarding special permission for our Saturday meetings. Be aware that this parking is controlled by the State college system therefore, exceptions to policy are rare. No practical solution seems possible other than to have a volunteer arrive a little early and stand by the pay device to assist members. **VOLUNTEERS CONTACT:** Gene@ipcs.org or phone 619-316-3354

Announcements

You are invited to visit our web-site at <http://ipcs.org>. You will be able to link to the latest studies in all aspects of Prostate Cancer. We also have developed a brochure which provides the group philosophy and explains important treatment considerations and health habits. Copies may be obtained at our

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meetings.

Gene Van Vleet has placed ads for our group in the Union Tribune and the Pennysaver. 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" More copies of the book "China Study" have been donated by Robert Werve. This is very informative reading. Bob Keck Librarian

SNAIL MAIL RECIPIENTS NOTICE!

We are spending over \$200 each month on US Postal Service mailings, so we would prefer to send Newsletters by e-mail. If you have a computer please log in to our website at <http://ipcs.org> and press the subscribe button. You will then get our mailings by e-mail.

IF YOU DO NOT HAVE A COMPUTER please let us know. Or if you can use a friend's computer, let us know and we will send our mailings to that address, which will save postage for the IPCSG. Also please let us know when you change your mailing address by e-mailing Gene Van Vleet at gene@ipcs.org or call Gene at (619) 316-3354 (we have to pay for mail returned because of a wrong address). If you no longer wish to receive this newsletter, please write to: IPCSG, P.O. Box 7033, San Diego, CA, 92167, or call Gene Van Vleet, 619-316-3354 E-mail gene@ipcs.org or, subscribers can click on the unsubscribe link at the bottom of the email cover to this Newsletter. Please include your reason for removal, for our records.

The Men's Club DVD

This video was produced locally by member Rocky Galgano with the help of our support group and a number of local doctors. It details all possible treatments including alternative and integrative methods for men and their families to discuss and choose. The full length video does not favor one treatment over another but rather gives a fair and independent revue of each treatment. **"The Men's Club"** has received favorable reviews from support groups nationwide. <http://themensclub.us/site/> to order OR purchase a copy from our library. IPCSG donated copies to all of the libraries in San Diego County where you can view it for free.

We Need Volunteers

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. Medical insurance. A committee has formed to develop a knowledge base to assist members in fighting their way through HMO's and getting new medications/procedures approved. Bill Pitts and Dennis Walker have volunteered.
2. 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.
3. Information Technology. Any techies out there that can help take advantage of the facilities available where we meet--such as live remote conferencing.

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4. Anyone interested please contact:

Gene Van Vleet, Director. 858-565-6253 gene@ipcsfg.org

Bill Geideck, Director, 619-993-7024 bill@ipcsfg.org

Lyle LaRosh, President 619-892-3888 lyle@ipcsfg.org

Medical Insurance Committee

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.

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@ipcsfg.com or cell phone 619-316-3354 who may redirect your inquiry to an appropriate person for response. PLEASE, PLEASE volunteer your effort to assist our cause.

If you are eligible and have not yet applied for Medicare, our knowledge may be helpful to you. Let us know if we can be of assistance.

PLEASE NOTE: Dennis Walker has made contact with a service that may be very helpful to you. There is a non-profit California organization that specializes in assisting you to obtain medical coverage that best suits your needs. It is called HICAP (Health Insurance Counseling and Advocacy Program). The San Diego number is 858-565-8772. Contact them if you need help making choices.

OUR MISSION

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CAVEAT EMPTOR

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The original and most valuable activity of the **INFORMED PROSTATE CANCER SUPPORT GROUP** is “networking” with fellow patients. We share our experiences, information, and attitudes, and we offer our support to men recently diagnosed---as well as survivors at any stage. Networking is sharing oneself with others for the good of us all. All aspects of prostate cancer are “controversial”. But by sharing our knowledge and experiences we learn the best and latest treatments for survival of this disease. So bring your significant other, and your input, 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://ipcsfg.org>, and clicking on “Donate” (*Ignore the invitation to join PayPal*). Then enter the amount and your credit card information and you are done.



Directions to Moore's Cancer Center at UCSD from I-5, Exit Genesee Ave. East to Regents Road, turn south to the first stop light (Health Sciences Drive) turn right at first stop sign (Voigt Dr.) that leads to the upper parking lot No. P703 on the left or P704 on the right.

Directions to Moore's Cancer Center at UCSD from I-805, Exit La Jolla Village Dr. west to Regents Road, turn North to Health Sciences Drive turn left at first stop sign (Voigt Dr.) that leads to the upper parking lot No. P703 on the left or P704 on the right.

Paid parking (\$1/hr) lot P761. Handicapped-Free.