



PCRI's First Dash4Dad - South Bay Race Successful!

CONTENTS



PCRI would like to thank everyone who came out to "Dash" at Dockweiler Beach Father's Day weekend!

Each year, hundreds of people participate in Dash4Dad races across the country to raise awareness for prostate cancer.

This year marked the first time the Prostate Cancer Research Institute teamed up with ZERO - The End of Prostate Cancer for the inaugural South Bay race in Southern California.

For race results and photos, see page 18.

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Chief Operating Officer*
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From the PCRI Staff

Cathy Williams,
Chief Operating Officer



Prostate cancer is different from all other cancers.

Many men will live long, healthy lives with prostate cancer as no more than a chronic condition. Education is vital to each man affected by prostate cancer, and necessary when making decisions about one's health and lifestyle. Each decision is unique to the individual. What is a great choice for one patient may not be the best for another.

Prostate cancer is a man's disease, and although it affects the whole family, ultimately it is the man who must live with it and the consequences of treatment choices.

PCRI understands the uniqueness of the disease, and empowers thousands of men to understand their treatment options. This is why we have decided to take a bold step forward and introduce the blue bow tie as a new symbol of prostate cancer awareness. The traditional blue ribbon has never been exclusive to prostate cancer, and is associated with over 20 health awareness programs. The blue bow tie, on the other hand, is as unique as the disease it represents.

You will see the bow tie in our new *Insights* logo and mentoring program. The bow tie has long been a symbol of intellectualism, and is typically associated with professors and teachers. Education is always at the forefront of PCRI, and our knowledgeable Helpline facilitators are available to take your call.

Thus, our new bow tie symbol speaks directly to our mission: *to improve the quality of men's lives by supporting research and disseminating information that educates and empowers patients, families and the medical community.* It also correlates with our five "shades" of blue, as the bow tie was first introduced in the Prussian wars of the 17th century, when Croatian mercenaries wore colorful scarves to denote rank.

What is most challenging about the bow tie is the tying itself! But with diligence in educating oneself, confidence will be achieved, and the same is true of prostate cancer.

Let us help you understand your options for wherever you may be in your prostate cancer journey. We are just a phone call or a click away!

(To receive a bow tie pin, please e-mail info@pcri.org or call us at 1-800-641-7274)



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Carbon-11-Acetate PET/CT Imaging in Prostate Cancer

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Fabio Almeida, MD

PET imaging of cancer metabolism is commonly performed with F18 fluorodeoxyglucose (FDG), and has become one of the primary tools in the evaluation of cancer patients [1]. This is based on the well-established understanding that many cancers are highly glycolytic, or have increased metabolism of glucose [2].

Although FDG may accumulate in aggressive and undifferentiated tumors, most prostate cancers demonstrate poor uptake of FDG, probably because most of these are well-differentiated tumors. Additionally, FDG is secreted into the urinary system, often interfering with pelvic pathologic findings and therefore significantly limiting its usefulness.

PET imaging of other metabolic pathways, such as amino acid or lipid metabolism, has now been explored in cancer. Fatty Acid Synthase (FAS) participates in controlling the lipid composition of cell membranes, and is over-expressed in many human cancers, particularly prostate cancer [5,7]. The degree of its over-expression appears to be correlated with tumor aggressiveness [6]. Among the different PET tracers that have been specifically evaluated for lipid metabolism imaging, Carbon-11-Acetate (C11-Acetate) demonstrates utility for detecting recurrent prostate cancer.

Recurrent & Metastatic Prostate Cancer

Unfortunately, recurrence of prostate cancer after treatment is frequent, occurring within 10 years in 20–50% of patients after radical prostatectomy (RP), and in 30–40% of patients after external-beam radiation therapy (EBRT).

Tumor recurrence is commonly assessed by a progressive increase of serum prostate-specific antigen (PSA) that typically precedes the clinically detectable recurrence. After RP, a PSA level of greater than 0.2 ng/mL, confirmed by two consecutive measures, can be associated with either residual or recurrent disease. After radiation therapy (RT), a PSA value of 2.0 ng/mL above the nadir represents persistent or recurrent disease.

Management of recurrent prostate cancer depends strongly on whether recurrence is confined to the prostatic bed (local failure), the regional lymph nodes in the pelvis or if distant spread has occurred. Although a trend of increasing PSA has been proposed as a way of predicting local recurrence versus distant recurrence, only imaging procedures are capable of discriminating between these scenarios [3,4].

Therapeutic options in recurrent and advanced prostate cancer are rapidly expanding. Thus, there is a need to develop imaging approaches that will a) allow for detection of and discrimination between local recurrence and distant metastatic disease, and b) permit the monitoring of tumor responses to these new therapeutic approaches.

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Standard imaging methods, including computed tomography (CT), magnetic resonance imaging (MRI), and bone scans (BS) are currently used, but none of these are very effective at detecting recurrences early enough to help select patients for salvage therapy with a curative intent. Additionally, these may limit the potential use of novel therapies by their inability to detect recurrences.

Several small studies have evaluated the relationship between serum PSA levels and detection of prostate cancer recurrence with C11-Acetate PET. In a study of 25 patients by Fricke et al, the degree of C11-acetate uptake was correlated with serum PSA levels [8].

Kotzerke et al evaluated a series of patients with suspected recurrence based on serum PSA measurements [9]. Trans-rectal ultrasound followed by biopsy served as the gold standard for C11-acetate PET imaging findings. C11-Acetate was true positive for disease recurrence in 15/18 patients with biopsy proven recurrence and was true negative in all 13 patients without recurrent disease by biopsy. Sensitivity was 83% and specificity 100%. Additionally, 4 of 5 patients with biopsy proven cancer and positive C11-Acetate PET imaging findings had serum PSA levels of less than 2.0 ng/mL.

Sandblom et al evaluated 20 patients with elevated PSA levels ranging from 0.5 to 8.1 ng/mL after radical prostatectomy [10].

C11-Acetate PET identified disease sites in 75% of the patients. In this study, all PET-positive patients had serum PSA levels of greater than 2.0 ng/mL. “False positive” findings were reported in 3 patients. One patient exhibited tracer uptake in the chest, which was subsequently confirmed to represent non-small cell lung cancer, while two other patients had inflammatory changes, one in the esophagus and the other in the mediastinum. As expected, this study suggested that C11-Acetate uptake is not cancer-specific, but rather, a probe of lipid metabolism which may also be altered in inflammatory disease.

Comparative Studies

A few groups have compared the diagnostic performance of C11-Acetate with that of other metabolic PET imaging probes in patients with prostate cancer. In a small study, Kotzerke et al evaluated 12 patients with prostate cancer [11]. C11-Acetate and C11-Choline, a substrate of choline kinase that is also incorporated into membrane lipids, were compared in patients after initial diagnosis, at the time of biochemical recurrence or after radical prostatectomy. The study found that C11-Acetate was not excreted into the bladder while urinary excretion was variable for C11-Choline. In terms of overall biodistribution and tumor uptake, the diagnostic performance of both imaging probes was found to be comparable.

In our own institution, we compared lesion detectability using FDG and C11-Acetate imaging

in a small group of prostate cancer patients with recurrent or metastatic disease [12]. Eighteen patients were imaged with both FDG and C11-Acetate PET with a PSA ranging from 0.32 – 13 ng/mL (mean 5.0ng/mL). C11-Acetate PET detected tumor in 14 (78%) of patients, whereas FDG PET detected lesions in only 2 (14%) of the imaged patients. In the two FDG PET positive patients, the PSA was relatively higher than in the other patients, with values of 7.8 and 11.15 ng/mL, respectively. C11-acetate PET was also positive in these two patients, detecting more disease with a significantly higher tumor to background uptake ratio. C11-acetate PET detected recurrence in the intact prostate or prostate bed in 5 patients, lymph node involvement in 6, bone in 4 and liver in 1. In 3 of 5 patients with lesions detected on C11-acetate, the PSA was < 1.0 ng/mL.

These studies suggest that C11-choline and C11-acetate appear to have a comparable accuracy for detecting local recurrence and metastatic disease in early PSA recurrence, while FDG PET does not seem to provide significant diagnostic value in this context.

Preliminary Results from the Arizona Molecular Imaging Center

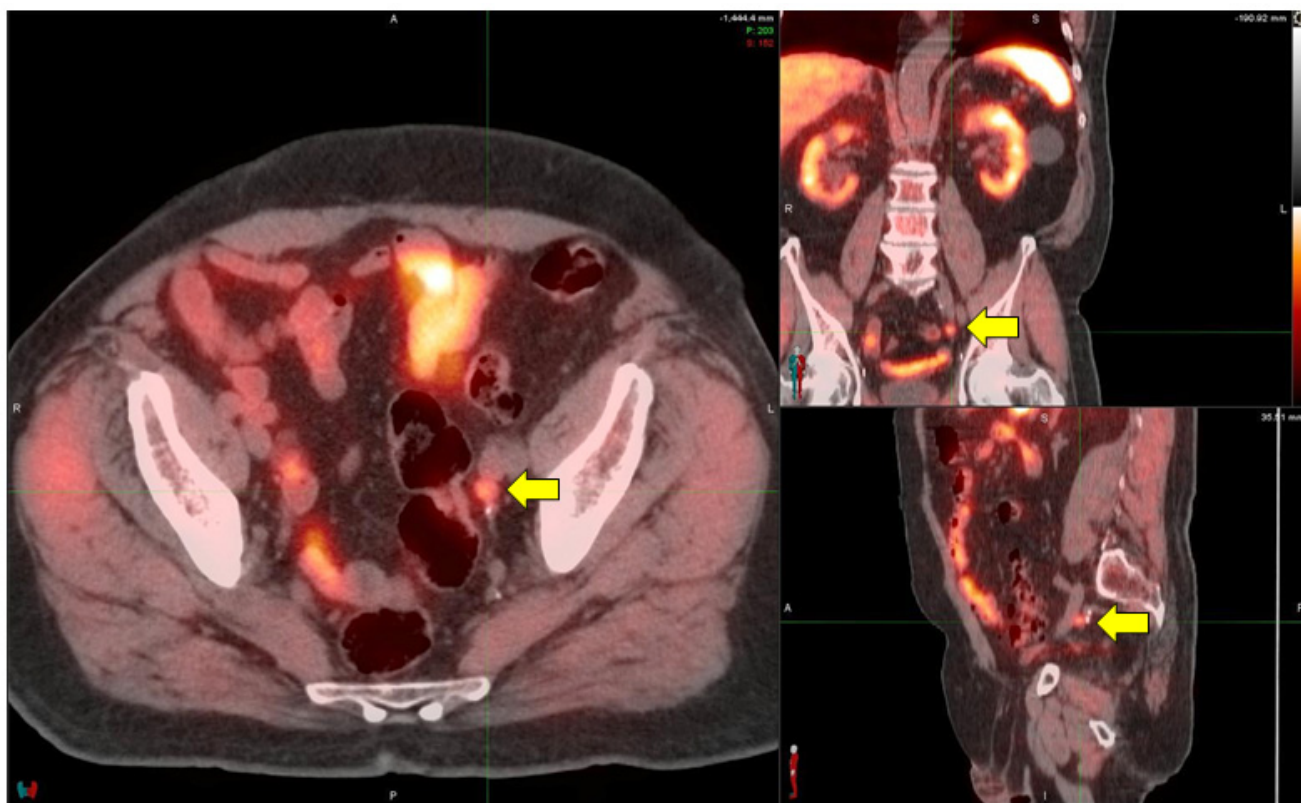
As part of an ongoing FDA-approved clinical investigation, the Arizona Molecular Imaging Center has thus far performed over 120 C11-Acetate PET/CT imaging studies, significantly more than have been previously published from a single institution in the U.S.

(continued on page 5)

Preliminary results from our studies have been very encouraging, and demonstrate a direct benefit to many patients that would not be achievable with any other standard imaging technique. See Case 1-3 below for examples of positive imaging studies.

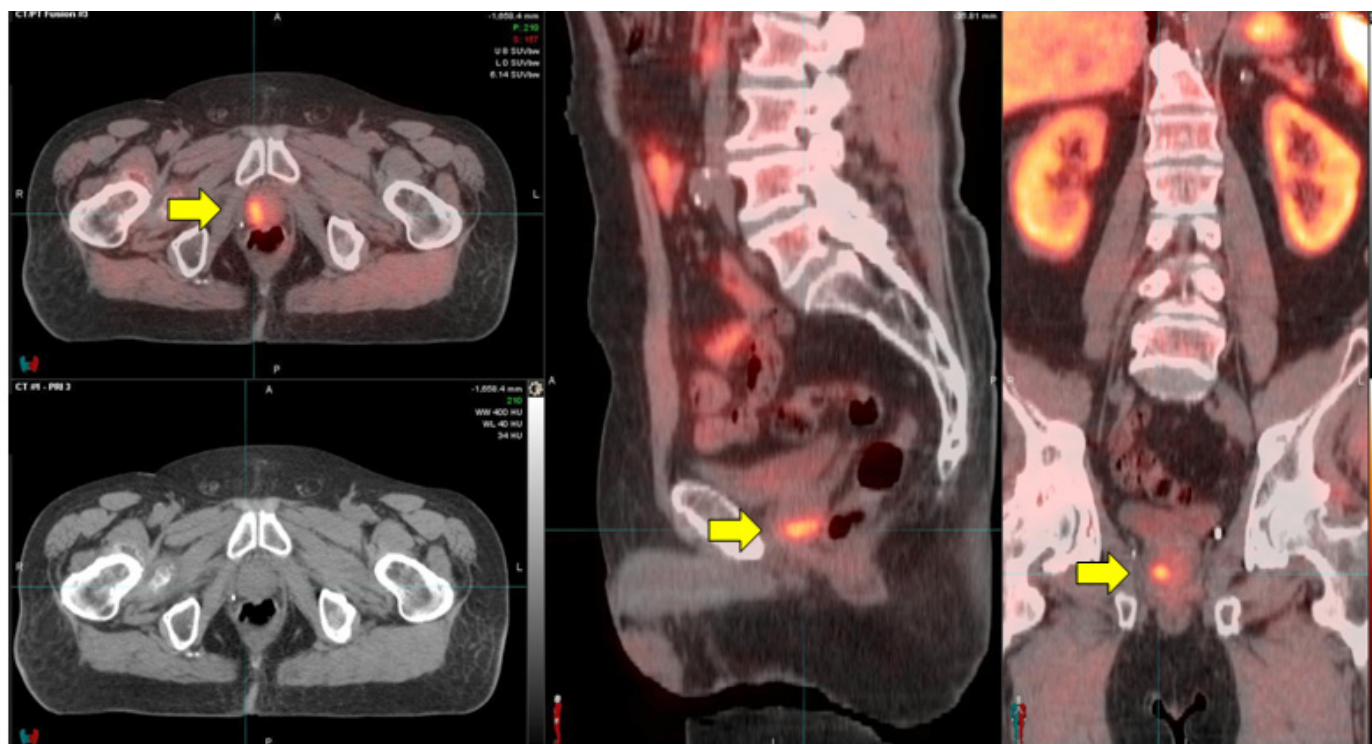
In our experience thus far, the overall detection rate of C11 Acetate PET/CT imaging for recurrent or metastatic disease has been 85%. When we separate the positive findings into various PSA levels, the detection rate has been 73% for PSA values of 0.4 – 1.0 ng/mL, 89% for 1.0 – 2.0 ng/mL and 93% for > 2.0 ng/mL. Our results to date have shown a higher detection rate than data from previously published studies, likely in part due to our use of more modern, state-of-the-art PET/CT imaging technology which allows for better detectability and localization of smaller lesions, and due to establishing a standardized imaging protocol based on tracer kinetics which had been lacking in prior studies.

Most of our study patients are still in early follow-up. However, in several patients with initial follow-up after additional therapy, such as radiation therapy directed toward the recurrence or metastasis, or after surgical removal of the lesion identified on the C11-Acetate images, there has been a significant decrease in PSA, confirming the accuracy of the C11-Acetate imaging.

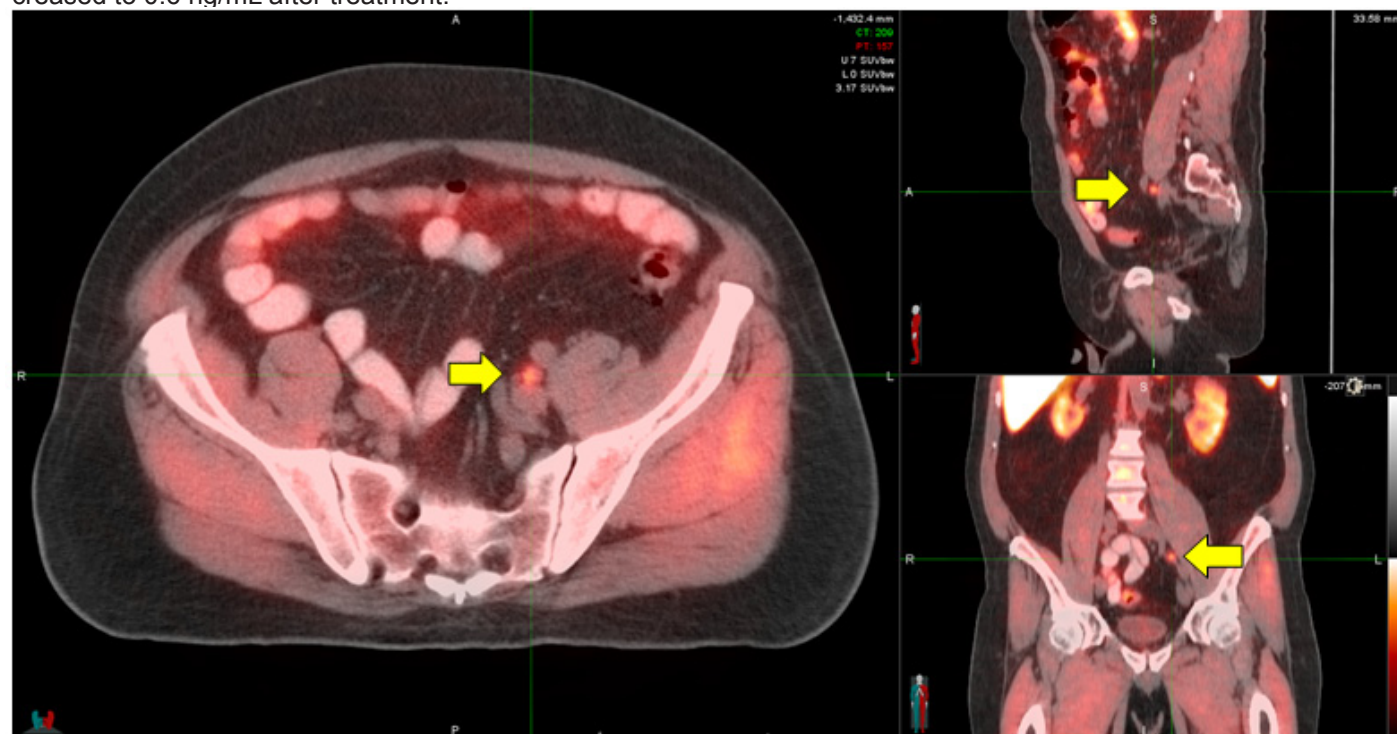


Case Example 1. Gentleman with prostatectomy 10 years previously. External beam radiation 1 year previously for a rising PSA. The PSA continued to increase up to 6.9 ng/mL. The 3 dimensional Carbon-11 Acetate PET/CT images show a small metabolic lymph node in the left pelvis (yellow arrows). This would not have been diagnosed on CT alone based on its small size. Other areas of 'red' seen on the images are of normal Carbon Acetate in the intestines, kidneys, liver and spleen. No other lesions were seen. The left pelvis node was treated with IMRT and the PSA then decreased to 0.9 ng/mL, confirming involvement of the identified node.

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Case Example 2. Gentleman with Gleason 7 prostate cancer and external beam radiation (EBRT) to the prostate 4 years previously. PSA nadir was 0.43ng/mL. Rising PSA to 3.9 ng/mL. The 3 dimensional Carbon-11 Acetate PET/CT images show a metabolic focus in the right side of the prostate gland (yellow arrows). No other lesions were seen. The prostate recurrence was confirmed by biopsy with subsequent Brachytherapy performed. The PSA decreased to 0.6 ng/mL after treatment.



Case Example 3. Gentleman with Gleason 6 prostate cancer. Brachytherapy and external beam radiotherapy 12 years previously. PSA nadir was 0.16 ng/mL. Rising PSA to 2.17 ng/mL. The 3 dimensional Carbon-11 Acetate PET/CT images show a single small metabolic lymph node in the left upper pelvis (yellow arrows). As in Case example #1, this would not have been diagnosed on CT alone based on its small size. Bilateral pelvic lymph node dissection was performed with 13 nodes removed. The node identified on the C11-Acetate imaging study was confirmed to be involve with prostate cancer (Gleason 4+4=8) and all other removed nodes were negative/benign, confirming the solitary finding on the imaging study. The PSA decreased to 0.19 ng/mL after the lymph node surgery.

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Due to recent changes in FDA regulations regarding new radiopharmaceuticals such as C11 agents, access to C11-Acetate now requires participation in an approved clinical study.

The Arizona Molecular Imaging Center has worked with the FDA to open an approved Phase II clinical investigation, and is pleased to offer Carbon-11-Acetate PET/CT imaging studies for localizing recurrent prostate cancer. Because this type of scan requires an on-site cyclotron, we are one of the few sites in the country capable of doing these studies, and currently the only FDA-approved private site for C11-Acetate.

Our center is equipped with state-of-the-art PET/CT imaging, which provides an extra advantage in the detection of small lesions. The C11-Acetate study requires only a single intravenous injection of the tracer and the imaging procedure can be completed in about 20 minutes.

For information about participating in this clinical trial, please visit the ClinicalTrials.gov website: <http://clinicaltrials.gov/ct2/show/record/NCT01304485> or call Dr. Fabio Almeida directly at 602.331.1771.

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Newly Diagnosed Prostate Cancer: Understanding Your Risk



Nathan Roundy
*PCRI Educational
Facilitator*

When the urologist calls with the life-changing news that your prostate biopsy is positive for prostate cancer, an office appointment is made to discuss your options.

This document will help you understand the new medical terms and jargon introduced at the newly diagnosed interview. Learn how your medical diagnosis details are applied to risk assessment tools to predict if you have low, intermediate, or high risk prostate cancer. Understanding your risk will guide you to making informed treatment choices.

- Most men newly diagnosed with prostate cancer will go on to live a normal life span.
- Many prostate cancers are Low-Risk (Sky shade), slow-growing and not very dangerous. Often, treatment can be safely delayed for years by following Active Surveillance, or relatively non-toxic treatments can be chosen. That avoids or delays possible treatment side effects such as impotence or incontinence.
- A few newly-diagnosed men have High Risk prostate cancer that is aggressive and potentially life-threatening. Those men may benefit from more aggressive therapy. They may accept the side effects risks in hopes of eradicating, or at least controlling their high risk prostate cancer.
- Men with Intermediate Risk prostate cancer have the hardest treatment choices. Their risk may be a little too high to be comfortable with Active Surveillance, while at the same time not being high enough to clearly indicate for aggressive therapy with its risks.

Obtain Your Medical Records

The clues to a man's prostate cancer risk (and his eventual treatment choice) can be found in his clinical diagnosis medical records.

One cannot understand his prostate cancer risk level without obtaining and understanding his medical records. Sometimes, a doctor's office is not set up to easily provide patients with copies of their records, and some additional 'prodding' may be needed to obtain the copies.

During the initial diagnosis office visit, the doctor will have your medical records chart on hand. This is a good time to ask for copies. A man has a right to his medical records, but a reasonable copy fee may be charged. Obtain the following records:

- 1. PSA History.** Make a log with the dates of all your PSA tests. Note any special events, such as "Suspicious Digital Rectal Exam (DRE)" or "Biopsy Ordered".
- 2. Urologist's Notes** that discuss the Clinical Stage from the Digital Rectal Exam (DRE), for example, T1c or T2b.
- 3. Ultrasound Report (TRUS) from the biopsy.** This is written by the urologist, and lists the size of the prostate in grams or cubic centimeters (cc). It may also indicate other risk factors.
- 4. Biopsy Pathology Report.** For each core, learn the Gleason Score, extent of disease in the core, and other important clinical diagnosis information.
- 5. Written Radiology Report(s),** if you have received any prostate scans such as CT, Bone, or MRI.

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QUESTIONS FOR YOUR UROLOGIST

The items below describe the clinical diagnosis details collected in the companion Risk Analysis Data Form. That data is used in the popular risk stratification tools such as D'Amico, NCCN, CAPRA and SHADES. Use those tools to understand if you have low, intermediate, or high risk prostate cancer. It is important to understand this is statistical risk derived from analysis of thousands of men. It does not precisely predict for the individual. For example many men with high risk are successfully treated, while some men with low risk may eventually have PSA rising after treatment.

It is important to understand we are talking about risk of PSA rising, not risk of imminent prostate cancer death. There are many effective treatments for rising PSA.

1. PSA at Diagnosis (just before positive biopsy): PSA 0 to 6 is very low risk, 6-10 low-risk, 10-20 intermediate-risk, >20 high-risk, and >100 is advanced disease.

2. Clinical Stage: Determined by the digital rectal exam (DRE):

T1c = no tumor felt with the finger (lowest risk)

T2a = small nodule on one side (low-risk)

T2b = larger nodule in more than half of one side (intermediate-risk)

T2c = nodules on both sides of prostate (intermediate/higher risk)

T3 = cancer detected outside of prostate but not invading local tissue (high-risk)

T4 = cancer invades local tissue such as bladder or rectum (high-risk)

3. Prostate Size (volume), in grams or cc: When the urologist performs a prostate biopsy, he or she uses an ultrasound machine to scan the prostate and aim the biopsy needles. At that time, they usually will also calculate the size of the prostate. Size can vary greatly, from less than 25 cc to more than 100 cc. Over 60 cc is enlarged enough to require special consideration when evaluating the radiation therapy options.

4. The PSA Density calculation ($\text{PSA} \div \text{prostate volume}$) takes prostate size into account. Enlarged prostates produce more PSA (even without cancer), and this higher PSA should be considered when evaluating risk. For example, a PSA of 10 places a man at intermediate-risk. But if the prostate size was 100 cc, most of that PSA may be coming from the large prostate, indicating that the man actually has a low-risk PSA. His PSA density would be normal at $10/100 = 0.10$. A PSA Density greater than 0.15 raises concern, because the PSA is high relative to the size of the prostate, and may indicate more extensive disease somewhere.

5. Age at Diagnosis: Take age (and overall health) into account when choosing a treatment option. Perhaps a man who is older or in ill health will choose less intense therapy in place of radical therapy and its side effects.

6. Highest Gleason Score Sum: The pathologist will assign a Primary Gleason Grade to the larger percentage involved, and a Secondary Gleason Grade to the lesser percentage involved in each biopsy core. The Gleason Score is the sum of Primary Grade + Secondary Grade (for example, $4+3=7$). Use the core with the highest score.

Gleason Grade 3 is the lowest grade normally reported as cancer, and is the lowest risk. When the cells look more different than healthy cells (poorly differentiated), they are assigned a higher Gleason Grade of 4 or 5.

Grade 4 and 5 cancer cells are more dangerous because they tend to invade local tissue or spread to the lymph nodes or bones. Greater amounts of grade 4 or 5 cancer in the prostate is associated with higher risk.

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For determining overall risk, the core with the highest Gleason score is used as the risk reference.

Gleason 3+3=6	lowest risk
Gleason 3+4=7	low-intermediate risk
Gleason 4+3=7	high-intermediate risk
Gleason Score 8, 9, 10	high risk

7. Number of biopsy cores taken

8. Number of biopsy cores positive: The more cores with cancer, the higher the risk that cancer might already be outside the prostate.

9. Percentage of Cores Positive = (number positive / total cores): More than 1/3 of cores positive raises the risk of cancer already outside the prostate. Over half of cores positive is high-risk.

10. Greatest core percentage of cancer found in the most involved core: If a core is more than 50% involved, there is more risk the cancer may be outside the prostate at that location.

11. Is there MRI , CT scan, or DRE evidence of Extra Prostatic Extension (ECE or EPE)? Cancer outside the prostate locally (stage T3) might still be eradicated, but more aggressive therapy may be required.

12. Any positive lymph nodes, within the pelvis, identified with MRI or CT Scan? Local therapy to only the prostate may not be enough. Research whether External Beam Radiation Therapy (EBRT) around the prostate and/or systemic therapy will be beneficial. (Stage N1, high-risk)

13. Bone metastases confirmed by a positive bone scan is Stage M1, advanced disease.

14. Any positive node beyond the pelvis? A metastasis in soft tissue outside the pelvis is high risk.

15. Comorbidities and other health problems, such as heart disease, diabetes or urinary retention, should be taken into account before initiating aggressive therapy. Perhaps the side effects of cancer treatment should be avoided, or less toxic therapies can be tried.

PCRI Helpline educational facilitators are specially trained to assist with understanding these medical records, and can be reached at **1-800-641-7274**, or **help@pcri.org** if you need assistance.

PLEASE SEE PAGE 13 FOR THE RISK ANALYSIS FORM. YOU MAY CUT OUT THIS FORM AND TAKE IT WITH YOU TO YOUR UROLOGIST'S OFFICE. ADDITIONAL COPIES MAY BE PRINTED FROM:

<http://prostate-cancer.org/pcricms/sites/default/files/PDFs/AYO-form.pdf>

DISCLAIMER – This document is intended to assist the prostate cancer patient to understand their disease diagnosis, and to outline questions to discuss with their doctor. It should never be considered actual medical advice.

Popular Risk Stratification Tools

In 1998, prostate cancer researcher Dr. Anthony D'Amico published an important paper that used statistical techniques to show that diagnosis PSA, Gleason Score and Clinical Stage (from the digital rectal exam) would predict if the cancer might come back after therapy. D'Amico risk stratification has since been validated in many scientific publications to predict risk of later cancer progression. Download the landmark 1998 paper for free at: <http://jama.jamanetwork.com/data/Journals/JAMA/4576/JOC80111.pdf>

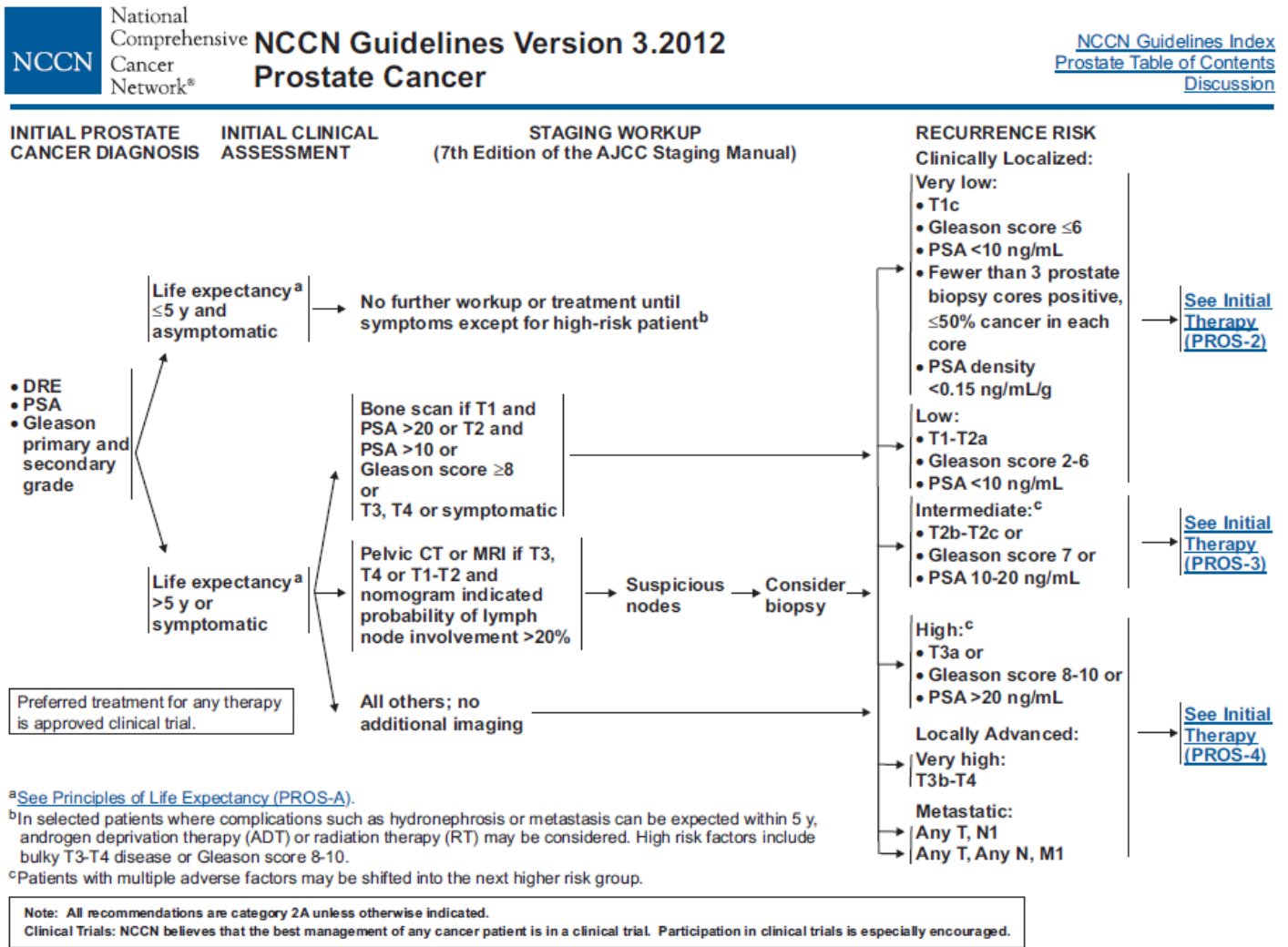
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D'AMICO PROSTATE CANCER RISK STRATIFICATION

D'AMICO RISK	LOW	INTERMEDIATE	HIGH
PSA	<10	10 TO 20	>20
GLEASON	≤6	7	8, 9, 10
STAGE	T1c, T2a	T2b	≥T2c
YOUR HIGHEST			

Circle your risk level for PSA, Gleason, and Stage. Your D'Amico risk stratification is the highest risk circled. For example, PSA 6 = low, Stage T2a = low, Gleason 4 + 4 = 8 = high. Highest = High Risk.

Later research showed that the percentage of cancer in the biopsy cores was also highly predictive of the cancer coming back after therapy. The National Comprehensive Cancer Network (NCCN) added core data to their risk stratification tool, which has also become widely used in reporting prostate cancer outcomes based on risk assessment at diagnosis. The NCCN tool also lists recommendations for when to get a Bone or CT scan to help identify possible prostate metastases. Download the NCCN Practice Guidelines for free at: <http://www.nccn.com/files/cancer-guidelines/prostate/files/assets/downloads/files/prostate.pdf>



Other risk stratification tools also add biopsy core data to better define risk. The CAPRA risk score is based on statistical outcomes from more than 10,000 men and has been validated both in the USA and in Europe, to predict risk, no matter which therapy is chosen. Read Dr. Cooperberg's *Insights* article for more information: http://prostate-cancer.org/pcricms/sites/default/files/PDFs/Is13-4_p3-7.pdf

The Prostate Cancer Research Institute SHADES risk tool also uses biopsy core data, and adds imaging data to the standard D'Amico risk assessment. In the following link, Dr. Mark Scholz discusses how to use the SHADES risk tool to help guide men to appropriate treatment options: <http://pcribc.org/pages.php?pageid=8>

	Local Therapy	Gleason Score	% Cores	Digital Rectal	PSA	MRI, CDU CT Scans	Bone Scan
Abn. PSA	No	No	No	T1c	2-10	Small Lesion	No Need
Sky*	No	<6	<33%	T1c, T2a	<10	No ECE	No Need
Teal**	No	7	33-50%	T2b	10-20	No ECE	Clear
Azure	No	8-10	>50%	T3	>20	ECE, SV, PN	Clear
Indigo	Yes	Any	Any	Any	Rising	Pelvic Node	Clear
Royal***	Any	Any	Any	Any	>100	Other Node	Positive

*One core > 50% replaced with cancer bumps to Teal

**Two yellow boxes bumps Teal to Azure

*** Any rising PSA with a low testosterone bumps to Royal

ECE = Extra-capsular Extension

SV = Seminal Vesicle

PN = Pelvic node

REFERENCES

Risk Stratification Forms*

Dr. Anthony D'Amico published the first widely recognized risk stratification scheme in 1998. Download for free here:

- <http://jama.jamanetwork.com/article.aspx?articleid=187980>

NCCN Practice Guidelines - Sign up for free access at <https://subscriptions.nccn.org/login.aspx>

- http://www.nccn.org/professionals/physician_gls/pdf/prostate.pdf

CAPRA risk stratification based on more than 10,000 men from 40 prostate cancer clinics.

- Risk Assessment for Prostate Cancer PDF - Matthew R. Cooperberg, MD, MPH 2010: http://prostate-cancer.org/pcricms/sites/default/files/PDFs/Is13-4_p3-7.pdf

SHADES

- <http://pcribc.org/pages.php?pageid=8>

**If you do not have access to the internet, please contact PCRI at (800) 641-HELP for the forms you need.*

NEWLY DIAGNOSED PROSTATE CANCER

Risk Analysis Data Form – Questions For Your Urologist

Get the data below from your urologist and/or your medical records. Then calculate your prostate cancer risk stratification using tools like the National Comprehensive Cancer Network (NCCN) Practice Guidelines, D'Amico Risk Analysis, CAPRA Score, and SHADES. See the companion Newly Diagnosed – Questions For Your Urologist instruction sheet.

Patient Name:	Diagnosis Date:
Doctor's Name:	Form Date:

1. PSA#: Just before positive biopsy	1
2. Clinical Stage: DRE result: e.g. T1c, T2a, etc.	2
3. Prostate Size: Volume in grams or cc. (Taken from biopsy ultrasound report)	3
4. PSA Density: = (PSA ÷ Prostate Volume)	4
5. Age at Diagnosis:	5
Biopsy Pathology Findings:	
6. Gleason Score: <u>Sum</u> of two Grades: e.g. 3+4= <u>7</u> (From core with highest Gleason Score)	6
a. Primary Gleason Grade: (1 st number)	6a
b. Secondary Gleason Grade: (2 nd number)	6b
7. Number of Cores taken:	7
8. Number of Cores Positive:	8
9. Percentage of Cores Positive: = (Cores Positive ÷ Cores Taken)	9
10. Geatest Core Percentage: In the core with the greatest % of cancer, what was the percentage (%) found?	10
Other Useful Data - Get Copies Of Written Reports	
11 Any ExtraCapsular Extension or ExtraProstatic Extension (ECE or EPE)? (locally advanced disease found with DRE, MRI, CT, or Color Doppler Ultrasound)	(YES) (NO) 11
12. Any pelvic lymph node positive? (Stage N1) (from MRI or CT)	(YES) (NO) 12
13. Any Positive Bone Scan? (Stage M1)	(YES) (NO) 13
14. Any positive node beyond the pelvis.	(YES) (NO) 14



ACTIVE SURVEILLANCE: A PATIENT'S JOURNEY



Mark Lichty
Prostate Cancer Patient

Note: This article is written from an active surveillance patient's perspective, and should not be considered actual medical advice or the opinions of PCRI. Please consult with your doctor(s) before making choices about treatment.

It has been more than two years since I shared my active surveillance journey in the March 2010 issue of *PCRI Insights*. In that article, I wrote that my father's over-treatment for prostate cancer resulted in a vastly decreased quality of life in his last year. His experience inspired me to opt for active surveillance (AS) when I was first diagnosed in 2005.

In the US Too Inspire online support network, I often read about men who have had intervention and are now dealing with the consequences, such as incontinence, erectile dysfunction and other uncomfortable side effects. Hearing about these experiences has reaffirmed active surveillance (AS) as a legitimate route for me.

My AS journey has taken me down many trails, and introduced me to a brotherhood of those similarly affected by prostate cancer. This is an update of that journey. I don't have all the answers for you about how to approach your cancer, but perhaps my experiences over the last seven years on AS may inform you in some way.

I have been encouraged by recent progress made by the medical community in accepting AS as a legitimate alternative to immediate intervention. Seven years ago, my choice of "watchful waiting" was viewed with skepticism and disapproval by my doctors and loved ones alike. Watching and waiting seemed passive to all of us, merely waiting for the cancer to do its dirty work. But when watchful waiting morphed into active surveillance - a minimum of intervention with a maximum of surveillance - I was all in. Now, AS is featured prominently on both the US TOO and PCRI websites as an alternative. Seven years ago, there was little mention of active surveillance as an option. As recently as two years ago, AS was not even mentioned on a nationally televised program that featured famous PC survivors such as John McEnroe. This reinforces the need for such progressive organizations as PCRI to carry the torch.

One of the greatest challenges for patients on active surveillance is finding support groups that cater to us. To their credit, PCRI has offered AS support groups at its annual conference, but I have found no such support groups on the East Coast. I recall chairing a PCRI support group when one man, nearly in tears, asked: "Where was this AS support group before I had my intervention?"

Us Too has developed an online support group, Team Inspire, where I have posted some questions and received thoughtful responses. Similarly, the PCRI Blue Community offers online forums for patients to discuss various treatment options with one another, including active surveillance.

The most significant event for me in the last two years has been the excruciatingly painful experience of not being able to urinate. Initially, my doctor suspected a urinary tract infection (UTI) and put me immediately on antibiotics. When the tests came back negative for a UTI, I was catheterized, resulting in a painful couple of days. It's interesting how our plumbing, which we take for granted most of our lives, awakens in our late 50s or so and says emphatically, like a spurned wife, *you know you have taken me for granted for all of these years, now I demand your attention.*

With this inability to pee, I was faced with a choice: I had to have either TURP or Green Light therapy. I prefer to avoid intervention whenever possible, but here I had no other option. My wife even suggested I get the prostate removed to eliminate potential problems and any risk of future cancer.

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I gave this notion a passing thought, but was still concerned about side effects. In addition, I have a sort of warped attachment to that troublesome little walnut. Removal didn't fit into my overall minimalist philosophy.

My research at the time focused on how many years the Green Light fix lasted, and initially it appeared to last about the same length of time as a TURP. Subsequently, I heard that the TURP may have a longer life span. I prefer outpatient procedures, and with the TURP I would have had to stay overnight, so I opted for the Green light. I still wake up several times a night to urinate. I have a bottle by the bedside so that I no longer disturb my wife by getting out of bed. Once one enters the brotherhood of the prostate, the simple act of urinating unexpectedly becomes a topic of much significance.

In retrospect, had I continued Avodart as my doctor advised, my prostate would have been smaller, and this whole incident may have been avoided. I had taken Avodart, but felt that it affected my sex drive and perhaps even my emotional state, so I discontinued. Was this a case where I relied too much on my own intuition? Should I have listened to the doctor? I will never know, but I am always cautious with drugs, as they have effects beyond what they are intended for - we call them side effects, but I prefer to drop the word "side."

The over-treatment epidemic is created by a variety of factors, including a legal/economic climate that nurtures this over-treatment (an issue which is discussed at length in the book *Invasion of the Prostate Snatchers* by Dr. Mark Scholz). So we have government agencies making recommendations not based on root cause analysis, but rather, on the notion that too much data is more than we can handle.

This points out the need for genuine participatory medicine. Both the patient and the doctor must step up to the plate.

In a New York Times article, Dr. Pauline Chen cites Dominick Frosch, lead author of a study on this subject, who stated, "Systemic changes to increase shared decision-making must be addressed... doctors' practices must be restructured to allow more in-depth conversation." When I was CEO of a corporation, I learned that infusing the air with my own ideas and prejudices would not empower those around me. We need to find ways to create these open vessels of caring conversation where empowerment can occur.

As I write about this notion of caring conversation, I think of my own conversation with my urologist seven years ago. I respect the man and count him as a friend. However, in a caring conversation context, I would have preferred that he step out from behind the desk, sit close by, take the clinical hat off, and after he shares with me that I have cancer, if he doesn't have time to spend with me, send me on to his nurse who would spend the necessary time providing me information about support groups, treatment options and other relevant information.

Of course, the conversation today would be quite different than it was seven years ago. At that time, I thought cancer was cancer. I didn't realize that some prostate cancers are slow-growing, and therefore may not be life-threatening.

Once our PSA starts to double or rise, the next step in the medical protocol is to undergo biopsy. There is an emerging PSA test, the Prostate Health Index (PHI), that may give us more information than the current PSA test. It combines 3 PSA's together – Total PSA, Free PSA, and 2Pro PSA. It has been used in Europe for several years, and may help AS patients in their surveillance process. PHI was cleared by the FDA in late June, but we are awaiting availability in the US. You can find more info at www.prostatehealthindex.org.

Rather than using biopsies, I have been monitoring my cancer with color Doppler and Magnetic Resonance Spectroscopic Imaging (MRSI). I was in a MRSI study at UCSF until funding dried up. My last MRSI indicated no cancer, but somehow a little voice in me believes that maybe it missed something. Unfortunately, MRSIs are expensive and not covered by insurance.

My experience has taken me to shamans, prayer, support groups and on many interesting journeys. It has been a synthesis of the East and West. I have shifted to a living food diet (primarily vegetarian).

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The vegetables alkalize my body, the theory being that cancer grows only in an anaerobic environment. I still believe that sugar feeds cancer, and I am in good company with folks like Dr. Lewis Cantley of the Harvard Medical School. My discipline on diet has faded with time, and my sons still get on my case about eating cake (or whatever sugary morsel tempts me). I am far from perfect, but I guess that makes me human. Cancer forced me to follow a diet that I might not otherwise have stuck to, and now my health, energy level and mood seem more consistent.

As I mentioned in my previous article, I have created a small online support group. One member, Paul, moved from a Gleason 6 to a Gleason 8 on AS and subsequently had radiation and hormonal therapy, moving through it with remarkable strength. He ran and exercised regularly during the entire course of therapy, which I believe was key to the grace with which he glided through that challenge.

Exercise is important for those of us on AS, but I admit that I am remiss here. I have done yoga for about 40 years, but could do more aerobics. I believe Paul is glad that he waited, as in the intervening 5 years from his diagnosis, options for therapy had improved. In fact, that is in part a motivation for many of us on AS to pursue it as we witness technological progress in medicine. This man's elegant handling of his transition from AS to intervention was an inspiration for me, and should be noted as a case study in how to transition from AS to intervention with faith.

Thus, my lesson from these past 7 years is that for low-grade prostate cancer, we can do active surveillance successfully and fearlessly. Support groups are a critical part of this journey, whether they are online or in person. Don't overreact to minor changes in your PSA. If you don't think you can make life changes such as diet, and exercise, intervention may be the choice for you. Once diagnosed, take your time, be patient with the process, do your research, and be at peace with your final decision, whatever it may be.

Tonight I listened to Steve Jobs' cancer story, and heard some criticism levied against him for not following more traditional medical protocol. I wonder if perhaps my loved ones may criticize me in the same way if my gamble doesn't pay off. In the end, I will know whatever happens, I did it my way.

Are you a federal employee?

Combined Federal Campaign (CFC) season is coming up!

Help us continue to provide valuable resources to men with prostate cancer by donating to the Prostate Cancer Research Institute via the Combined Federal Campaign!

PCRI believes that a patient who understands his disease and treatment options will be empowered to communicate more effectively with his physician(s), and will obtain a better outcome. PCRI uses all available communication tools and programs, including a Helpline, a quarterly and a weekly newsletter, website and professional conferences to educate men about prostate cancer.



PCRI undergoes an annual financial audit, and consistently receives a "Best in America" seal of approval from the Independent Charities of America.

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Of the 1 million charities operating in the United States today, it is estimated that fewer than 50,000 – or 5 percent – meet or exceed these standards, and, of those, fewer than 2,000 have been awarded the Seal. We appreciate your support!



Use the following information to make a contribution to PCRI as part of CFC:

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Congratulations to our first class of participants!

Congratulations to all who helped make our first-ever mentor program a success!

PCRI proudly recognizes the spring/summer 2012 group of mentors:

Dennis Bogarad
Teresa Denham
David Derris
Ann Dodelin
Jim Edmonds
Doug Ferrero
Ken Foster

Russ Gould
Allison Harvey
Marcel Koppel, MD
Ron Kramer
Anant Kulkarni
Rich Laethem
Lyle LaRosh

Stan Mikkelsen
Joel Nowak
Wes Sholes
Lonnie Silva
Richard Swanson
Russ Thomas
Gene van Vleet

Thank You to our Speakers!

PCRI could not have completed the pilot program without the time and generosity of our faculty:

Tom Kirk
Mark Scholz, MD
John Mulhall, MD
Mark Moyad, MD
Daniel Margolis, MD
Laurence Klotz, MD
John Blasko, MD
Charles "Snuffy" Myers, MD
Richard Lam, MD

What is the Mentor Program?

Support groups are often one of the first places men turn to for help and guidance when they are diagnosed with prostate cancer.

PCRI is proud to offer a new **online training program** that is targeted specifically towards the leaders of these support groups, and features webinars by some of the world's most respected physicians on the different stages of prostate cancer and treatment options.

The Mentoring Program covers all the complex topics a man may encounter on his prostate cancer journey, including men's health, screening and biopsy, imaging, sexual side effects and much more.

*Interested in becoming a PCRI Mentor? Call **310-743-2116** or e-mail **info@pcri.org** for more information!*



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Rebello Jordan
Raymundo Rincon
Rutilo Chavez
Ron Graham

WINNERS

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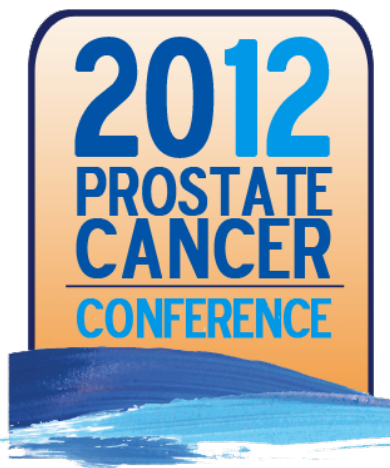
Rachel Ragona
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Join PCRI and ZERO in the fight against prostate cancer at our next Dash4Dad race Father's Day weekend 2013!



Dash4Dad - South Bay 2012





Can't make it to the 2012 conference?

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The Prostate Cancer Research Institute depends on **your donations** to keep our programs running, including our annual conference, which is the only patient-centered prostate cancer conference in the United States, and attracts more than 700 attendees every year.

If you have ever taken advantage of the many services we offer to men with prostate cancer and their families, please consider donating to one of our areas of education, advocacy and research:

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