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CHOICES

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AMERICA: BEWARE THE URORAD

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A Strange Place

Changing Your Lifestyle

What the Heck Has Been Going On In My World

and More!

Life Without Prostate Cancer:
Imagine The Possibilities!

PAACT, INC.

PROSTATE CANCER COMMUNICATION

CHOICES

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1143 Parmelee NW
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President…Richard Profit
Editors….Richard Profit/Molly Meyers
Staff….Molly Meyers, Jill Beckwith
Webmaster….Omega Systems

Postmaster: Send address changes to:
Prostate Cancer Communication
P.O. Box 141695
Grand Rapids, MI 49514

Phone: 616/453-1477
Fax: 616/453-1846
E-Mail: paact@paactusa.org
PAACT Web Page: www.paactusa.org
Newsletter: www.paactusa.org

EDITOR:
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Dispose of Meds Safely

By Dr. Ranit Mishori

Leftover medicine has a way of making trouble. Flushed down the drain, it pollutes lakes and rivers as well as our drinking water. Kept at home, it's a poison risk for small kids and teens. And passed along to a family member or a friend, it encourages people to dose themselves without a prescription. None of this is good.

Of the more than 4 billion prescriptions written yearly, it is estimated that some 40% go unused. That's about 200 million pounds of meds—including those in liquid form.

To help dispose of unused medications properly, the National Community Pharmacists Association has launched a "Dispose My Meds" campaign. More than 800 community pharmacies in 40 states have signed on. It's easy. Just bring the drugs to a participating pharmacy, and it will send them to a medical-waste-disposal facility. Or you can get a postage-paid envelope from the pharmacy and mail the drugs from your home.

Go to DisposeMyMeds.org for details and to find a pharmacy near you.

Originally printed in PARADE July 4, 2010

TABLE OF CONTENTS

Dispose Of Meds Safely ... 2

America: Beware The Urorad
Michael j. Dattoli, MD ... 3

A Strange Place: An Information Guide To Prostate Cancer
By T.R. Herbert ... 5

Letter To The Editor ... 12

What The Heck Has Been Going On In My World-Part 31!
By Mark A. Moyad, MD, MPH ... 12

Bladder Management After Prostate Cancer Treatment
By Bioderm ... 15

Caring For Your Bones When You Have Prostate Cancer
By Susas F. Slovin, MD, PhD ... 17

Changing Your Lifestyle Can Change Your Genes
By Dean Ornish, MD ... 19

Medicare To Pay For Cancer Drug ... 21

2011 Prostate Cancer Conference ... 21

Contributions And Acknowledgements ... 22

Financial Summary Report ... 23

PAACT Membership Form ... 24

AMERICA: BEWARE THE URORAD

MICHAEL J. DATTOLI, MD

(*Disclaimer* – The author is a well-known, board-certified radiation oncologist, who has pioneered combination radiotherapy for prostate cancer and fueled its maturation over two and a half decades. His practice is limited to prostate cancer exclusively, and offers the most exquisitely refined and focused DART radiation, generally coupled with brachytherapy. Because of his reputation and extensive publication of results, his center consistently draws patients from all over the world who have researched his work. While the circumstances exposed in this article are changing the "landscape" of local prostate cancer care, his practice remains exceptionally busy. *This article is intended to educate the many thousands of unknowing prostate cancer patients who are inclined to merely follow their urologist's lead in choosing treatment for their disease.*)

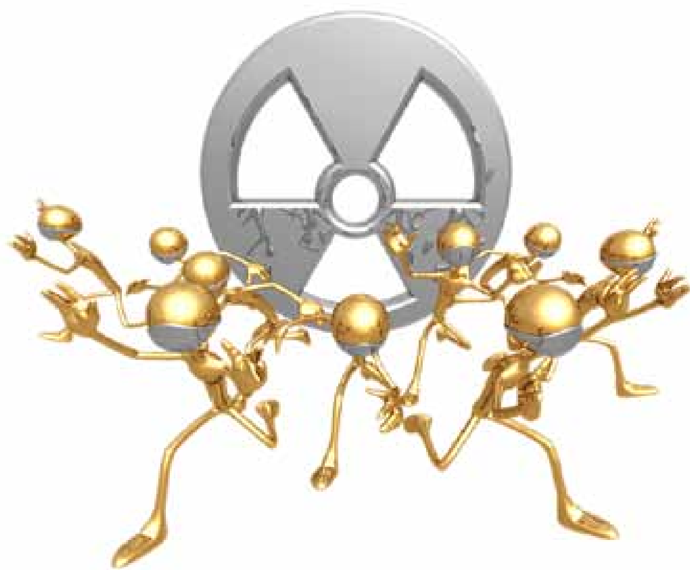
Are you aware that an egregious scam is being perpetrated upon prostate cancer patients, right under our noses and with the complicity of the federal government? This may seem hard to believe but I assure you it is true and it is coming to your town, in fact it is probably already there. I am referring to the "UroRad" phenomenon that has cropped up in all but 9 states the last 4-5 years. What is an UroRad? The term refers to the alarming number of radiation oncology treatment facilities around the country that have been created by urologists.

These vastly popular and growing affiliations mesh two diametrically opposed medical specialties: urologists and radiation oncologists. Over the past two decades, these two factions have independently of each other (and often in fierce competition with each other) forged the two most popular and successful treatment modalities for prostate cancer, namely Radical Prostatectomy and Radiation Treatments. As in most businesses (and remember prostate cancer treatment is a business, after all) competition is and has always been a good thing.

Urologists, who only a few years ago roundly condemned radiation as treatment for prostate cancer, are now proud owners of radiation centers and are happily **steering** their patients who ask about radiation as an alternative to surgery to "their radiation centers." One might ask "how" (or better, "why?") they made the 180-degree change in their opinion. Here's a hint: it has to do with preserving and increasing the urologists' revenue flow. But in the process, this bizarre union blatantly flies in the face of the Stark Anti-Kickback Legislation, enacted by Congress in 1992, and has been documented to lead to over-utilization of services and undermining the **best interest of prostate cancer patients.** This is what concerns me.

So, I say beware of the urologist who appears unbiased in his recommendation for you to receive either surgery or radiation, since this urologist is financially rewarded no matter which option you choose: a win/win situation for the urologist without regard to what is best for the patient.

I'll explain: Urologists essentially act as gatekeepers for the prostate cancer patient population. When indicated by the PSA test and/or digital rectal exam, the urologist performs prostate biopsies to confirm a diagnosis. It then becomes the urologist's responsibility to discuss treatment options with patients and, when appropriate or requested, to offer referrals to specialists at other institutions. Depending on the approach chosen by the patient, due to his medical training and board certification the urologist can legitimately act as the specialist performing surgical intervention and/or hormonal management. But what happens when the patient is astute enough to ask about radiation (either external, internal seeds or a combination of both)? The UroRad urologist can conveniently refer the patient to "his center," and prevent losing that patient as a fee-paying entity. These UroRad centers may or may not have the best equipment (many have simply refurbished equipment) and often the patient's treatment plan may be farmed out to a central facility providing a "one size fits all" treatment design. The UroRad center most likely will not employ specially trained or highly experienced *prostate radiation specialists*, but simply radiation generalists who are networked with that urologist. These groups of urologists are benefiting financially through joint venture facilities utilizing external beam radiation (and rarely seed implants), which by law can be performed only under the auspices of a radiation oncologist. A radiation oncologist must be "on-site" for this to be legal, although he or she doesn't need to be board-certified (or demonstrate any particular advanced prostate radiation skill).



This is patently in defiance of the Stark Law which was enacted to prevent self-referral "kickbacks" between medical specialties. This would be tantamount to having your prescribing physician very specifically and sometimes even forcefully referring you to a pharmacy *which he owns*.

Here is the crux of the problem: Urologists are *not* trained in radiation therapy and have absolutely no connection with the actual clinical administration of radiation. Due to the recent joint ventures in which urologists have a vested financial interest and managerial role, these centers have a deleterious impact on a patient's choice of treatment. The urologist and radiation oncologists have partnered in order to be able to offer a sophisticated form of external beam radiation therapy, Intensity Modulated Radiation Therapy (IMRT), which is now reimbursed by Medicare at a higher rate than surgery. Medicare will reimburse for IMRT as much as $40,000 (depending on the geographical location). By contrast, Medicare reimburses about $7,000 for a radical prostatectomy or $1,500 for seed implants (not including the hospital stay). IMRT has been clinically proven to be safe and extremely effective *when administered by experienced radiation oncologists at centers of excellence*. A growing number of studies suggest that IMRT (often coupled with seed implants) is superior to surgery and other forms of treatment for intermediate and higher risk prostate cancers, and is also superior in salvage situations following failed prostatectomy.

The Medicare Payment Advisory Commission (MedPac) recently released figures for Medicare payment for radiation therapy for cancer to physicians outside of hospitals who were not radiologists or radiation oncologists. Between 2003 and 2008 (the advent of UroRads) reimbursements for this therapy skyrocketed 84% - to $104 million! (Rob Stein, *Washington Post,* February 28, 2011.) Another analysis found that reimbursements for seed therapy plummeted in one community after the UroRad center opened in 2007.

Clearly there is a mounting problem here. These UroRad affiliations believe they are legal in view of a loophole in the Stark Law, as long as they maintain an "office" onsite at the radiation center. In fact, these offices may be little more than a cubicle for billing purposes. Most commonly the urologist and radiation center share the same Federal Tax ID number, to potentially protect themselves from Medicare fraud and abuse charges (which upon further investigation is not the case.) As reported in the recent *Washington Post* article, "The U.S. Government Accountability Office is launching a probe into the practice of self-referral nationally that will focus in part on IMRT for prostate cancer."

The areas of concern for not only investigators but for patients are:

1) The financial agreements at these self-referral centers effectively rob patients of their ability to make fully informed choices with respect to treatment. The bottom line is that these facilities enable the UroRad to give a "one-stop shop" of IMRT or surgery under one roof, frequently without educating/offering patients other viable treatment options (such as Brachytherapy, cryotherapy, active surveillance and others) or referrals to superior centers of excellence, which could literally be in the same town or even next door!

2) These urologist-owned centers ultimately compromise the quality of medical care. In a profit-oriented self-referral setting, where is the incentive to provide the highest level of quality care? It should be noted that radiation oncologists employed by these centers are in turn guaranteed referrals, and many of these radiation oncologists may have little or no previous experience with IMRT. They are witting accomplices to the urologists at the centers, while the urologists reap the lion's share of the profits.

3) These urologists are financially motivated not only to deliver a diagnosis of prostate cancer in as many patients as possible but also to treat as many patients as possible. In addition, the urologists themselves have gone so far as to hire "on-site pathologists" to review pathology and increase the number of cancer diagnoses (often to the elderly and infirm), again with a fee-splitting arrangement.

   According to the same *Washington Post* report cited above, "Jean M. Mitchell, PhD, a health economist at Georgetown University, is planning to soon publish a study showing that urologists who perform – and receive payments for – their own pathology services are more likely to order biopsies and to take more tissue samples for analysis." This also raises the specter of an "in-house" pathologist diagnosing high grade PIN or ASAP (findings which either mimic or are precursors to prostate cancer) to actually be malignant.

4) The management of post-treatment complications (which may increase with inexperienced personnel delivering the radiation) can be extremely costly (both in regard to dollars and patient outcome), and again, the urologists are able to take advantage of their self-referral monopoly by managing the complications (i.e. more revenue), while their radiation oncologist 'employees' assume full liability.

5) The self-referral facilities nationwide are contributing to the destabilization of existing treatment markets, which is likely to bring about further reductions in quality of care. These joint-venture facilities are causing major losses for hospital-based programs that are already suffering in terms of patient referrals.

6) The profit motive on the part of these urologists is shamefully transparent. One consortium based in Texas, UroRad Healthcare, sells complete packages of IMRT equipment and services to urologists. As profiled in the *Wall Street Journal* on December 7th, 2010 (John Carreyrou and Maurice Tamman),

UroRad Healthcare promotes a business model for urologists, suggesting with marketing hype, "Through the integration of IMRT services, urology practices can potentially double or triple their practice revenue." It is reported that each urologist who gets on board with this program and depending on the number of prostate referrals to the radiation center, can potentially "realize an additional $500,000 of net revenue!"

Indeed, this is the worst scandal that I have witnessed in the medical field during the entire course of my career. In illustration, one urologist's greed was so profound that he told the patient who had inquired about treatment outside of the urologist's purview, that not only would he dismiss him, but he would contact other local urologists and urge them to never accept this patient should he require future urologic management and care. This is nothing short of the patient being blacklisted in his community.

I believe that it is the right of all patients to have access to the best medical care available. The urology-owned radiation oncology concept allows profit to subvert quality of care. The model allows for one type of specialist to literally take over another specialty, and exploit it for financial gain. This sets a very dangerous precedent. Both Congress and the Office of the Inspector General, as well as state governments in Maryland and New Jersey, have expressed serious concerns and issued a call to action regarding urologist-owned facilities in light of the Stark Law and anti-kickback legislation. Unfortunately, however, they are going up against "big money" and highly paid lobbyists.

My advice for patients and others concerned about the future of medicine in this country is to wake up to these abuses. I advise all patients that if the urologist is suggesting a treatment that he or she does not do personally, such as sending you to a radiation center, *ask if you are being referred to a facility in which he or she has a financial interest*, and hence, stands to gain an illicit profit from your treatment. When that is the case, the best advice for patients is what the Romans used to say, "Caveat emptor – Let the buyer beware."

This UroRad business is ugly, potentially harmful to patients, illegal and must be stopped. The federal government must close this dangerous loop hole by removing the ancillary exemption clause which is being taken advantage of by financial opportunists, better known as your local urologists and radiation center co-conspirators. Add your voice to its defeat by contacting your state and federal representatives – *now!*

Michael Dattoli, MD
Sarasota, Florida

If readers would like specific details of how the Stark Law is being perverted to allow the UroRad to proliferate and profit, please feel free to contact my office for more information. Dattoli Cancer Center & Brachytherapy Research Institute - 2803 Fruitville Road; Sarasota, FL 34237 • 1-877-328-8654

A STRANGE PLACE

AN INFORMATION GUIDE TO PROSTATE CANCER

T.R. HERBERT

This article is a booklet being printed in a multi-part series. The next series will begin with GETTING STARTED – THE PROCESS which will discuss PSA, Biopsy and additional tests and scan. It will also include staging and diagnosis. At the conclusion of this multi-part series it will be made available in its original format as a booklet.

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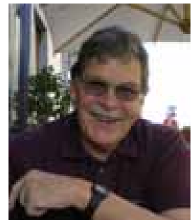
Acknowledgement is made, and thanks given, to Donna Pogliano; members of the Prostate Support Action (PSA) Group and the YANA - You Are Not Alone Now website and members of my family who assisted in the final editing of this booklet. And to members of the YANA site for their generous donations that made this edition possible.

This document is supplied free of charge to those who need it. A donation will ensure that more copies are made.



Terry Herbert, the author of this article, has no medical training. He was diagnosed as having prostate cancer in August 1996 and has learned something about the subject since then. In 1998, with colleagues Gregg and Kerry Morrison he established a website - YANA - You Are Not Alone Now at www.yananow.net. The stated aim of the site, which is still active, is:

"To provide comfort to any man diagnosed with prostate cancer, to offer thoughtful support to him and his family and to help them to decide how best to deal with the diagnosis by providing them with and guiding them to suitable information, being mindful at all times that it is the individual's ultimate choice; that the path he decides to follow is his own and that of his family, based on his particular circumstances."

This booklet is primarily for those who do not have access to the website. Its aims are the same as the website.

INTRODUCTION
The Golden Rule of Prostate Cancer 2
HOW LONG HAVE I GOT? HOW SOON WILL I DIE? 2
HOW WILL I DIE ? 4
Two important things about prostate cancer 5
PREPARING FOR THE JOURNEY
How will I know if I have prostate cancer? 6
Basic language hints 6
GETTING STARTED - THE FOREST OF FEAR
The important facts about all medical tests 7
Collect and keep the paperwork 8
Travelling companions 8

INTRODUCTION

A diagnosis of prostate cancer is shocking. Life will never be the same. Everything changes. You feel lost; you don't know what to do.

The late Robert Young, who was diagnosed in the latter part of 1999 with a PSA of over 1,000 ng/ml, compared it to being dropped, without your consent, into a new country where the language, customs, terrain, roads and rules are all foreign. You are in a **Strange Place**, and it's frightening.

This book is intended, like a good travel guide, to help men (and their partners and those who are close to them) to find their way around this **Strange Place**. From it they can learn some of the basic language, customs and options, including the Golden Rule:

THE GOLDEN RULE OF PROSTATE CANCER IS - THERE ARE NO RULES

The process of diagnosis is subjective, with significant variances in the interpretation of test results: the choice of the most appropriate treatment is difficult because of a lack of good comparative information; the outcome of any treatment is variable.

Despite the lack of rules, this book should enable them to find a path through the **Forest of Fear** to **Diagnosis**. They will be able to cross the **Doubtful Desert** to get to **Treatment** and to decide which option may suit them best. It will take them through the highs and the lows of the **Plains of Recovery** and may help them deal with the side effects of treatment. It will give them a significantly better chance of reaching the final goal of **Remission**.

What follows is not intended to take the place of the more personal and detailed information and advice, which can only come from a trained medical advisor. Its goal is to provide a better understanding of some of the basic aspects about the diagnosis and treatment of prostate cancer.

Ideally, all men who have prostate problems, an elevated PSA (Prostate Specific Antigen) or even those men having their annual DRE (Digital Rectal Examination) and PSA check-up will read this book. This would help them deal more easily with the issues they may face in the event of warning signs being discovered or if they have a positive diagnosis for prostate cancer.

Before exploring this new country and all its features, it should be said that the normal reaction to a diagnosis of prostate cancer is one of shock, dismay, fear and confusion. But uppermost in the minds of most men who have just been diagnosed with this disease are two questions:

HOW LONG HAVE I GOT?
WHAT IS IT LIKE TO DIE FROM PROSTATE CANCER?

How long have I got? How soon will I die?

The terrifying thing about the word "cancer" is its association with an inevitable and often painful death. Many men on hearing that they have prostate cancer assume that it is a matter of days or weeks until they die. They are wrong!

Less than 5% of men diagnosed with prostate cancer will die from it within ten years of their diagnosis. The life expectancy of most men will not be changed by the diagnosis. They will live until they die of something else - most notably a heart attack. A recent study, using US statistics, indicated that in a 20 year period more than 87% of men diagnosed with prostate cancer would not die from the disease.

Prostate cancer can, and does, kill thousands of men each year throughout the world. It should not be underestimated or treated lightly. But many more men survive the disease than succumb to it. It is important to know that.

Although the immediate focus, on hearing the word 'cancer' applied to us concerns the prospect of dying from the disease, the subject is something of an Elephant In The Room. It rarely comes up for discussion on Internet Lists or Forums and if it does is greeted with a hushed silence. There is very little published material - yet it is the main driver behind all decisions to do with the disease - **"How long have I got?"**

Many doctors avoid these issues, if they can, because they are difficult enquiries to answer. If they do respond, the question and answer that is remembered by the patient may not 'match' what the doctor said. Patients often qualify the question by asking *"How long have I got? What is the worst case, doctor?"* The doctor's answer may be along the lines that although some men with advanced prostate cancer may only live three to five years, most men, even men with aggressive disease, will live for many years; that the actual outcome depends on many factors; and so on. But what the questioner remembers is ***"Three to five years."*** And that is almost certainly the wrong message.

There are no definitive answers to these questions. There are too many variables: prostate cancer is not a simple 'one size fits all' disease. These variances result in significantly different diagnoses and outcomes. Some say that there are two varieties of the disease - the very aggressive 'tigers' and the not so worrisome kitty cats. But in fact there is a very large feline community in this Strange World, including kitty cats, feral cats, wild cats, lynx, bobcats, servals, caracals, cougars, jaguars, mountain lions, pumas, cheetahs, leopards,

lions and tigers. They all represent different variants of the basic disease. The way in which the disease prowls, attacks and spreads can vary from man to man, depending on a wide number of factors, such as genetic background, diet, body mass, or exercise.

These are some of the issues that have a bearing on life expectancy after diagnosis:

THE DIAGNOSIS.

Although the terms used will probably not be understood at this stage all are covered later in this booklet and are recorded here only for completeness.

A **"bad"** diagnosis - the tiger of the family - carries a high, but not a 100%, chance of early rather than late death. It will generally be associated with a number of pointers. They are a combination of high Gleason Score of 8, 9 or 10; a history of continuously sharply rising PSA numbers; a low free PSA percentage (under 15%); a high PSA level, well over 20 ng/ml and probably in the hundreds; a staging of T3 or T4. Such a "bad" diagnosis carries a high, but not certain chance of early death.

At the other end of the range is the **"good"** diagnosis - the kitty cat - carrying a very low risk of death, but not a zero risk. Typified by a Gleason Score of 6 - the lowest score for a diagnosis; a history of small or no continuous increments in PSA levels; a high free PSA percentage (over 25%); a PSA level below 10 ng/ml; a staging of T1. Such a diagnosis carries a very low risk of disease specific death, but not a zero risk.

These diagnostics are variable - for example there is a very dangerous form of the disease - you might liken it to a leopard - with a low PSA level that is often only diagnosed late in the day through DRE (Digital Rectal Examination) or the development of symptoms because the PSA levels generated never hit any of the levels that are defined as "abnormal" - this will be covered later in the book.

AGE AT DIAGNOSIS.

The latest available statistics show the median age at death for cancer of the prostate was 80 years of age. That is to say, half the men who died from prostate cancer were more than 80 years of age. The figures also show that over 90% of the men who died were over the age of 65. The same statistics show the median age at diagnosis for prostate cancer was 68 years of age with about 62% being men over the age of 65. Or to put it another way, although almost 40% of the men who were diagnosed were under the age of 65, only 10% of the men who died of the disease were under this age.

There is a view that any form of the disease diagnosed in a young man - usually regarded as a man in his late 40s to mid 50s - is more likely to be a 'tiger' and aggressive, but this is not supported by available data. What has been established from the limited data available is that a young man with a "good" diagnosis will have an even better survival rate than an older man, while if he has a "bad" diagnosis this is likely to progress more quickly than a similar diagnosis in an older man.

RISK OF OTHER CAUSES OF DEATH:

Overall, despite the statements in publicity material, prostate cancer is not a major killer of men. In most Western countries, such deaths account for only about 3% of male deaths (which means that 97% of men die from some other cause) and, generally speaking, even men who have been diagnosed with prostate cancer still have a higher risk of dying from some cause other than this disease.

Two recent studies illustrate this point. The first, published in 2008 was a study of 19,271 men aged 66 years or older diagnosed with clinical stage T1-T2 prostate cancer (down towards the "good" or kitty cat end of the range). During the follow-up period - a little under 7 years - almost two thirds of the men died, but relatively few died from prostate cancer. Causes other than prostate cancer accounted for 11,045 (88%) of all deaths and far fewer - 1,560 (8% of the men in the study) were from prostate cancer.

The second study is an ongoing one on Active Surveillance (the term for decision not to have immediate treatment) and interim results were published in 2009. The median follow-up in this study of 453 men, was 7.2 years. In that time 77 (17%) of the men in the study died but only 5 (1%) died from prostate cancer. The ratio of non-prostate cancer to prostate cancer mortality was therefore 16:1. The men in this study had diagnoses similar to the "good" diagnosis set out above.

It is important to understand that much of the available information will refer to 'average' or 'median' life expectancy. Many people do not understand these terms which are used interchangeably, but which are in fact different. Stephan Jay Gould wrote an excellent piece titled "The Median Isn't The Message" - after he was diagnosed with a form of cancer (not prostate cancer) with a median life expectancy of only eight months, yet he lived for 20 years after his diagnosis. He explains:

Consider the standard example of stretching the truth with numbers - a case quite relevant to my story. Statistics recognizes different measures of an "average," "mean" or central tendency. This mean is our usual concept of an overall average - add up the items and divide them by the number of sharers (100 candy bars collected for five kids next Halloween will yield 20 for each in a just world). The median, a different measure of central tendency, is the half-way point. If I line up five kids by height, the median child is shorter than two

and taller than the other two (who might have trouble getting their mean share of the candy). A politician in power might say with pride, "The mean income of our citizens is $15,000 per year." The leader of the opposition might retort, "But half our citizens make less than $10,000 per year." Both are right, but neither cites a statistic with impassive objectivity. The first invokes a mean, the second a median. (Means are higher than medians in such cases because one millionaire may outweigh hundreds of poor people in setting a mean; but he can balance only one mendicant in calculating a median).

So, while none of the three factors discussed above can, in themselves, produce a firm answer to the question "How long have I got?," taken together they can help to give an indication of the range of potential survival time for an individual. He can assess where his diagnosis fits into the range; how old he is; what his general state of health is and what his work and leisure activities are. Hopefully in completing this exercise he will come to the conclusion that he has many years ahead of him; that he will realise that there is indeed life after Prostate Cancer and that he will understand that this is still primarily a disease of old men, at least as far as death is concerned. As Willet Whitmore, a prostate cancer specialist, said many years ago: *"Growing old is invariably fatal while prostate cancer is only sometimes so."*

HOW WILL I DIE?

Many people shy away from the second question - ***"How does death come?"*** because the word "cancer" is emotionally laden. It is usually associated with a drawn out, painful death and this is particularly so as far as prostate cancer is concerned, when metastasis (spread) to the bone can create significant pain, so let's deal with that first.

There is no doubt that bone metastasis can, and does happen to a minority of men and it is an awful fate for them and their loved ones. In the few discussions that have occurred on the Internet, experts in the field of prostate cancer have said that modern pain management techniques can deal with most of the issues and that, in any event, the dreaded painful bony metastasis is less common than imagined, at least in their experience.

A piece written by Dr Michael Glode (Professor of Medical Oncology M.D., Washington University), on his blog in October 2007 says in part:

"Prostate cancer tends to spread to lymph nodes or bones. There are some studies that begin to show us why this is different in different patients but have yet to lead to more practical management decisions.

We treat all metastases first with androgen deprivation. In those patients with nodes, we keep the urethras open as they may be compressed by the enlarging nodes. Without these interventions, the kidneys can stop working and lead to death from accumulation of toxins normally excreted in the urine.

For those patients in whom bone metastases dominate, the main issue is often pain management. Radiation to bones that have tumor deposits can be extremely helpful along with appropriate pain medications. It is highly unusual to have a patient in whom pain cannot be well controlled with radiation, opiates, NSAIDs and attentive care."

A response to a discussion of this subject on the Internet said in part:

"I am a hospice social worker who was diagnosed with prostate cancer in 2005. So I have two perspectives on the disease, as a survivor and an individual who has provided counseling, emotional support, education and advocacy to patients dying from prostate cancer. The focus of hospice is to maximize a patient's quality of life while assisting him/her with the transition from this life. Prostate cancer patients generally enter a hospice program when they have six months or less to survive. ***The majority of PC patients who have died under my agency's care went peacefully with a minimal amount of physical pain and emotional stress.****"*

There is a somewhat irrational fear that use of opiates to deal with pain will lead to addiction. Dame Cicely Saunders, regarded as the founder of the modern hospice movement, had a clear view of that. As a nurse, she knew that, as she said, "dying is hard work" and she transformed the way we look at death and dying, ridiculing some of the medical profession for not giving large doses of pain-killing drugs on the grounds that they might become addictive. If the patient were dying anyway, what did it matter? Nor did she believe that drug doses big enough to remove pain entirely would necessarily cause the patient to develop such a tolerance to the drug that it would become ineffective. Regrettably many medical institutions and doctors still hold outmoded views and too many people suffer unnecessarily if they are not aware of these issues and are led to believe that there can be no relief from their pain.

Dr Michael Glode's blog also refers to hospice care when he continues:

"The thing that leads to death in most patients, however, is not direct involvement of an organ like the liver, lungs or brain. Instead, most patients seem to have a "wasting syndrome" not unlike AIDS. Loss of appetite, loss of energy and general debilitation lead to weight loss and patients don't feel like getting out of bed. Hospice care can be extremely helpful for this stage of illness and is usually available either at home or in an inpatient facility."

The wasting syndrome to which he refers can come from emotional issues like depression but is usually from Cachexia

or Anorexia (not to be confused with the anorexia nervosa of young women). If caught early on, anorexia may be treated and weight loss reversed with nutritional supplements or increased consumption of food. In prostate cancer patients some molecular causes of cachexia are now known and work is being done to try to address these, but cachexia does not respond to nutritional supplementation or increased consumption of food.

One final point. People who reach this 'end of life' stage will often have fought against the disease for some time and they, and their doctors, may misjudge how long they have to live. One study showed that Doctors who referred terminally ill patients to hospice care were consistently incorrect. In only 20 percent of cases were their predictions accurate.

TWO VERY IMPORTANT THINGS TO REMEMBER ABOUT PROSTATE CANCER

Because of the high survival rates and the relatively slow progress of the disease in most men:

One: No one should give up hope as far as this disease is concerned. The journey to recovery or remission through diagnosis and treatment can be a long and hard one. It is made easier by the knowledge that there is a good chance of successfully completing it.

Two: There is time for men and their families to educate themselves about the disease and then to work with their medical team to make the best choices they can.

PREPARING FOR THE JOURNEY

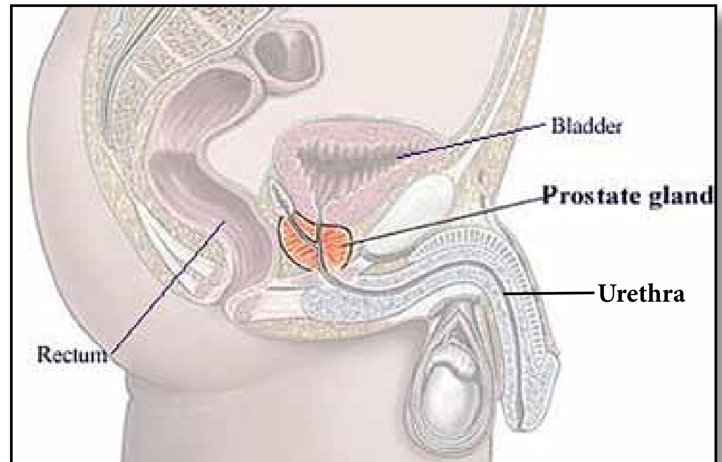
To help you orientate yourself in this **Strange Place**, you might want to know the answer to these two questions:

WHERE IS MY PROSTATE GLAND? AND WHAT DOES IT DO?

That's not as silly as it sounds. Most men don't know where the prostate gland is, even though only men have them. This is not really surprising. It is one of the best- protected glands in the human body; it rarely causes any trouble until after the age of fifty and it is not very big - about the size of a walnut. So why would you know where it is?

The prostate gland will usually have a volume of about 25 cc's which is the same as a weight of 25 gms. It is contained within the bony structure of the pelvis and is very close to the bladder and rectum. In fact the duct that empties the bladder (urethra) passes through the prostate. This means that both prostate disease and treatment of the prostate gland after a diagnosis of prostate disease can cause problems with urination.

The main function of the prostate is to provide the fluid that carries the sperm on ejaculation. The nerves that control erections are along the sides and at the base of the gland. Damage to the nerves during treatment can, and often does, cause erectile dysfunction or impotence. This means that attaining an erection can be difficult or impossible after treatment. New techniques have reduced the incidence of erectile dysfunction, but most men will have some erectile problems after treatment. The degree of erectile dysfunction can vary significantly and may be temporary or permanent depending on the individual, the treatment option chosen and the skill of the person carrying out the treatment.



The relative positions of bladder, prostate and urethra

HOW DO I GET TO THE STRANGE PLACE?

So, how do you get to the **Strange Place?** What's the procedure? Let's start with some background information to answer frequently asked questions:

HOW WILL I KNOW IF I HAVE PROSTATE CANCER - WHAT ARE THE SYMPTOMS?

Most prostate cancer diagnosed today is termed asymptomatic - there are no symptoms. In most cases, diagnosis occurs after a routine examination, including a PSA blood test. If the PSA level is elevated, the normal process of diagnosis follows as described below.

Where there are symptoms, they are likely to include urinary problems (like frequent or painful urination, difficulty in starting urination, blood in the urine), problems with erections and ejaculation (such as pain or discoloured ejaculate) and pain in the bones.

But before worrying too much about these symptoms, it is important to know that many other diseases less dangerous than prostate cancer, such as infection of the bladder or prostate (prostatitis), can be responsible for many of them. Nevertheless, anyone with these symptoms should seek medical advice - and sooner rather than later.

Older men tend to have some urination problems - often frequency and urgency issues. The most common cause is BPH (Benign Prostatic Hyperplasia) or enlargement of the prostate. As the prostate grows it restricts the channel that

passes through it carrying urine from the bladder. BPH is not a malignant disease and often starts showing up when men reach their 50s. It can be dealt with by means of procedures such as a TURP (Transurethral Resection of the Prostate), TUNA (Transurethral Needle Ablation), TUMT (Transurethral Microwave Thermotherapy) or with drugs. A herbal treatment known as Saw Palmetto has been reported as being helpful in relieving some of the symptoms of BPH, as have pumpkin seeds.

The only way prostate cancer can be diagnosed with any certainty is by a biopsy of the gland. Before that happens there are usually some preliminary steps. These are described below. In reading them you will start to learn some of the language and customs that might be new to you.

WHAT CAUSES PROSTATE CANCER?

No one can answer this question, but one school of thought links inflammation of the gland to a potential for tumour to form and grow. Even if this is not correct, there is general agreement that a healthy life style - good eating habits, correct weight, exercise, stress reduction - will lead to a lower probability of prostate cancer and may well inhibit the growth of any tumours. A healthy life style would also help in the recovery process after any treatment.

CAN PROSTATE CANCER BE SPREAD TO MY PARTNER FROM OUR SEXUAL ACTIVITY?

There is no evidence that cancers can be spread in this way.

BASIC LANGUAGE HINTS

Before moving onto the diagnostic procedures, there are some basic language issues to be learned. Firstly and most importantly, many words have acquired specific meanings in this Strange Place-meanings that differ from those you may have attached to the words in the past.

The best example, perhaps, is the use of the words "positive" and "negative." In your usual "pre-cancer" place, broadly speaking, positive = good and negative = bad or not good. These positions are somewhat reversed in **Strange Place** talk.

You soon learn that a positive result to a test is not one you want to have. A positive result means that there are definite signs of the disease. On the other hand, as you are frequently told, a negative result does not mean you are disease free. There are merely no positive signs. So in this **Strange Place**, positive = bad and negative = not positive.

Another very important word to understand is "cure." This word has many meanings in the **Strange Place**. There is rarely agreement amongst medical practitioners who often use differing definitions of "cure" for the same therapies. A study published in 2008 found over 200 definitions of "failure" so that means there are as many definitions of "cure."

The achievement of a "cure" follows observation for signs of any recurrence of the disease once it has been treated. This is true of all treatments, including surgery and can stretch over a period of many years, making the journey a long one. For many people the main goal is "remission" - a freedom of any signs of the disease - rather than "cure."

Even the word "cancer" can be misleading. To quote Dr Christopher Logothetis, a leading specialist in advanced prostate cancer: "One of the problems with prostate cancer is definition. They [the pathologists] label it as a cancer, and they force us all to behave in a way that introduces us to a cascade of events that sends us to very morbid therapy." This view is shared by well known and respected pathologist Dr Jon Oppenheimer who believes that there should be a clear distinction between what we call the aggressive forms of the disease and what we call those that are less likely to prove fatal.

There are other words and phrases you will need to understand. Many are three-letter acronyms, such as PSA, DRE and HDR: some are two- and four- letter acronyms such as RP, SI and EBRT. All of these will seem tremendously confusing at first, but will hopefully become clearer as you learn the language. **For easy reference you will find a short glossary of common terms and expressions at the back of this book.**

GETTING STARTED - THE FOREST OF FEAR

Going through the process of diagnosis is a frightening experience for most. Tests are ordered, often without any apparent reason or explanation; results are given in language that is difficult to interpret or understand; and all the time the fear grows. Hopefully, this section will take some of that fear away from the process. There is also often a feeling that time is limited, that a decision regarding treatment must be made very soon after diagnosis. For the vast majority of men the window of opportunity for successful treatment is a wide one and decision-making may safely take some months.

THE FIRST IMPORTANT FACT ABOUT ALL MEDICAL TESTS

No test is always 100% accurate.
Diagnosis is not an exact science.

The degree of error can vary considerably, depending on the complexity of the test - and some tests are very complex indeed. Sophisticated machinery is used for some - the maintenance of the machinery can alter the result. Chemicals are used in other tests - the use-by date of these chemical agents can alter results. Technicians run the tests - their training can alter results. The outcome of all tests needs to be interpreted by a specialist - their expertise can vary.

All this adds up to a degree of uncertainty and explains why it is very important to have all results checked by the most knowledgeable person available - and why second opinions should be sought automatically.

THE SECOND IMPORTANT FACT ABOUT MANY MEDICAL TESTS

The value of many medical tests lies in measuring the change in the results, not the results themselves.

Thus for PSA tests, it is important to measure the size and speed of any change from prior results, since this gives an indication of the aggressiveness of the disease. To get this measurement it is necessary to have a series of tests at regular intervals. This may mean delaying the start of treatment but the information is invaluable.

AND THE THIRD IMPORTANT FACT

mistakes can be made

The medical world is no different to any other place. Human beings run it and they can make mistakes. Get copies of all test results - ensure they are yours. If an unusual result does not relate to other results, have a re-test in case a mistake has been made.

Collect and keep the paperwork

Studies show that people who take an interest in the diagnosis and details of their disease and who involve themselves in the process of selecting the most suitable treatment have the best chance of recovery.

Appointments with medical advisors are often confusing, and sometimes rather rushed, affairs. Many people feel they do not want to waste their doctor's time and sometimes doctors give the impression their patients are indeed doing just that. But whether the time with the medical people is long or short, the information will often be bewildering or overwhelming. It is a good idea therefore to:

- Make notes before the appointment of all the issues you want to discuss or ask about;
- Attend all appointments with a companion - two heads being better than one for the interpretation of the information;
- Take a portable tape recorder to the appointment and record what is said, if the doctor is agreeable - you will then have time to gain a greater understanding of what was said when you play back the tape;
- Not be reticent in expressing reservations, asking for the rationale for a suggested course of action or determining the likely side effects. Ensure that you receive all the information you will need to make your decision.

It is very important to obtain, study and keep copies of all medical reports. Try to understand what they say and what they mean. If anything isn't clear, ask for more information and keep asking until you understand. It may be difficult for a medical person to reduce the complexities of a diagnosis to simple, non-technical terms, but you are entitled to this, so keep at it.

It is also a good idea to check reports for factual errors. Even typing errors can be a cause for concern and lead to misunderstandings. It may not be of great importance if the report records your age incorrectly. Whether a man is circumcised or uncircumcised does not affect the diagnosis or choice of treatment. But if this type of detail is wrong, there may be other errors, on the technical side, that are not so obvious.

TRAVELLING COMPANIONS

The diagnosis and treatment of prostate cancer affects not only the man with the disease, but also his wife or partner and family. It is particularly hard on the womenfolk. A woman is not only concerned about her man, but also about her own future without him - and often feels guilty about this. It is much more difficult to deal with these issues alone than it is with the support of other people. Family and friends should be told and be involved in the process of sifting information and coming to a decision. A word of warning here - the help offered by well-meaning people can be somewhat overwhelming at times, so it may be best to keep the circle of helpers small initially.

Support groups - terrestrial or in the cyberworld - can provide invaluable encouragement and advice. Most men and their companions who join support groups speak highly of the comfort in knowing they are not alone, and being able to speak to people who are on the same journey they are. Even talking to strangers can help - many men have traveled this way before and most will be only too pleased to pass on what they have learned. By taking these steps some of the feeling of "aloneness" is dissipated. It is worth asking your doctor or making enquiries at your local hospital to find the nearest support group.

Diagnosis with a potentially life-threatening disease can cause tremendous emotional upset - there is sorrow, anger, fear for the future and a whole host of aspects that must be worked through. The combination of these can often lead to the development of clinical depression which is very difficult to deal with alone. Men are notoriously reluctant to seek professional help for mental conditions like this but should get to a counselor. It will assist in regaining their balance.

If you have access to the Internet, join one of the discussion lists or forums and ask questions. The collective knowledge of the men and women on these lists is substantial and very few questions cannot be answered. Above all, never be concerned about appearing 'stupid' in asking a question. The only 'stupid' questions are those not asked.

Letter To The Editor:

As Medical Director of Oncology at Centocor Ortho-Biotech, I wanted to respond to comments made in the December, 2010, Issue of the PAACT Newsletter, regarding the topic of dosing abiraterone with and without food.

While final labeling has been approved by the FDA, we anticipate that directions for use of this product will be to take 1 g (four 250 mg tablets) as a single daily dose that must NOT be taken with food, and should be taken at least two hours after eating and no food should be eaten for at least one hour after taking. The tablets should be swallowed whole with water.

THE EFFECT OF ABIRATERONE ACETATE TAKEN WITH FOOD HAS NOT BEEN SUFFICIENTLY STUDIED; THEREFORE, ONE SHOULD NOT TAKE ABIRATERONE ACETATE WITH FOOD AS THE EFFICACY AND SAFETY OF DOING THIS IS UNKNOWN, POTENTIALLY DANGEROUS AND COULD LEAD TO UNFORESEEN TOXICITY OR OTHER ADVERSE EFFECTS FOR PATIENTS. PHYSICIANS AND PATIENTS SHOULD NOT DEVIATE FROM THE DOSING RECOMMENDATIONS IN THE PRODUCT LABEL.

Respectfully Yours,

Scott Barrett, M.D.
Director, Medical Oncology, Medical Affairs Division
Centocor/ Ortho Biotech, Inc, Horsham, PA

WHAT THE HECK HAS BEEN GOING ON IN MY WORLD-PART 31!

BY MARK A. MOYAD, MD, MPH, UNIVERSITY OF MICHIGAN

Note: A total of 53 times in a row I have written and volunteered for this newsletter, and I have yet to receive any financial compensation or personalized gifts for my efforts. I recently received multiple kind letters that were sent to the PAACT office that expressed their concerns that perhaps I needed at least a free beer, soda (or should I call it "pop") or low calorie dinner for my efforts. Personally, I want to thank all of my fans around the world (I think there are 4 total fans, which includes my mom, dad, wife and dog when I provide him with a treat and yell "squirrel!") because without you I could not make PAACT feel guilty for working me harder than Charlie Sheen's public relations agent!

BREAKING NEWS STORY #1!

194) Abiraterone (also known as "Zytiga") in combination with prednisone gets FDA approved for men with metastatic, castration-resistant prostate cancer that is no longer responding to chemotherapy (taxotere…).

(Reference: www.medscape.com/viewarticle/741780)

BOTTOM LINE:

Abiraterone (a pill that you take daily) prolongs life in these men, so thank goodness it got FDA approved. The side effects are remarkably low with this drug. The most common side effects were fluid retention (edema) in 30% of patients and liver function tests abnormalities occurred in about 10% and cardiac problems occurred in about 12% of men.

WHAT ELSE?

Nothing else for now, just ask your doctor about this drug, especially if you are currently receiving chemotherapy for prostate cancer or you are no longer responding to chemotherapy.

BREAKING NEWS STORY #2

195) New immune system enhancing ("boosting") drug (called "Yervoy") to treat metastatic melanoma received FDA approval on March 25, 2011, and it may fight other cancers in the future (including prostate cancer).

(Reference: www.yervoy.com)

BOTTOM LINE:

The second immune boosting drug in advanced cancer gets approved and this is exciting. The first one that got approved was for prostate cancer (Provenge). Several studies are beginning to show that "Yervoy" (interesting name) may also treat prostate cancer, so watch this drug carefully!

WHAT ELSE?

This new drug is now known commercially as "Yervoy" (also called "ipilimumab," but Yervoy is easier to pronounce so I am going to stick with that name) and it will be marketed by Bristol-Myers Squibb Co. of Princeton, NJ. There are not very many effective drugs to treat late stage melanoma. Yervoy works by blocking a switch that a cancer can use to keep the immune system from recognizing that cancer itself, so the drug works by enhancing the immune system response of your body! This is also one of the "catches" of the drug because it allows your immune system to be really boosted or put into 5th gear so to speak, and so a minority of patients (about 13%) suffered from serious autoimmune reactions in clinical trials because the immune system also attacked some non-cancerous tissues. Still, this was not common, but is an example of how well the drug works to increase your immune response. Another "catch" that some critics point toward is the 4-month increase in median survival with this drug, but keep in mind that this is a "median" survival, which means that 50% of the patients lived a little to a lot longer than 4 more months. In other words, I think this is a very big step in cancer research, because it will be interesting to see how effective this drug really is when it comes to treating earlier stages of melanoma, and other cancers because an immune drug is less likely to work when the cancer is advanced. Vaccines or immune therapies work better in general when it comes to preventing a disease, or when there is less (not more) disease in the body to fight. This is also due to the ability of the cancer to escape the immune system response as the disease progresses. So, the fact that this drug worked at all in patients with metastatic melanoma is very exciting. And, there is excitement in other cancers such as lung and prostate cancer because this is an immune boosting therapy that is in clinical trials right now with two diseases and hopefully others in the future. Yervoy is being tested with conventional treatment in earlier and later stages of these and other cancers. Stay tuned! Immune therapy or immune enhancing treatments for cancer are really beginning to receive good research and attention.

196) Fish oil continues to receive more interesting and beneficial research in cancer. This is a whale of a story! (I apologize - had to make a silly and ridiculous joke related to fish).

(References: Siener R, et al. J Urol 2011;185:719-724; Murphy RA, et al. Cancer 2011, published on-line early. Murphy RA, et al. Cancer, 2011-published on-line early-second article in the same issue; Szymanski KM, et al. Am J Clin Nutr 2010)

BOTTOM LINE:

At least 4 new studies suggest fish oil may reduce kidney stone risk, may help prevent muscle loss, and might improve survival in some cancer patients taking approximately 1000-2000 mg of the active ingredients (EPA & DHA) daily. Also, there is one more thing my friends that you need to know about medical studies. Never let 1 negative study that hits the media convince you that most positive studies are wrong. In other words, medical research is like a courtroom in that the majority of the evidence usually points in the direction of truth (except in that older television series "Matlock" where he always had just a little bit of evidence but still never lost a case). Once in a while you may hear a study about eating fish or fish oil and how it may not help or may hurt cancer patients, but this does NOT eliminate all the heart healthy and overall healthy benefits of fish for most people including cancer patients. In other words, 1 negative study is just that, 1 negative study. It does not represent the majority of the evidence for fish and should not be treated as fact. This is what happened with cholesterol and prostate cancer because there were a few studies a long time ago that suggested that low cholesterol might increase your risk of prostate cancer, but it was found that some men with low cholesterol had advanced prostate cancer that was using up some of the cholesterol in the body! So, it was not the low cholesterol that was causing prostate cancer, but it was probably the prostate cancer that was causing the lower cholesterol number! Today the majority of the evidence points toward heart healthy = prostate healthy or that a low cholesterol may reduce the risk of getting aggressive prostate cancer. This is what the majority of the evidence points toward. It does not mean it is 100% fact, but it does suggest that it would be smart to keep your cholesterol low in order to reduce your risk of the number 1 cause of death in men and women (cardiovascular disease), and it might also help battle or fight prostate cancer. If I see 1 or 2 studies that shows that smoking does not dramatically increase the risk of lung cancer in some people, or that seat belts do not save that many lives, that is never going to get me to start smoking and not wear a seat belt. Sorry for CASTING such a wide NET on FISH OIL, but I was trying to BAIT YOU into reading more stuff toward the TAIL end of this article.

WHAT ELSE?

In one recent study participants ingested fish oil supplements with a total omega-3 content of 1500 mg (combination of 900 mg EPA and 600 mg DHA) per day. Upon completion of the

30-day study, fish oil supplementation caused a significant (p = 0.01) reduction in oxalate, and the potential risk of a kidney stone. This small study supports several earlier studies that fish oil (1-2 capsules/day) may protect against kidney stones or kidney stone recurrence. Another study of 40 patients taking about 2000 mg of fish oil for 10 weeks during chemotherapy for lung cancer found a significant increase or maintenance in muscle mass and weight, and it appeared to also improve survival. Men on hormone therapy for prostate cancer could theoretically achieve the same muscle sparing benefits. Another summary of past studies found a reduced risk of prostate cancer mortality or death in men that consume fish.

What else can you tell me about fish Dr. Moyad? I am glad I asked myself that question folks! Fish oil supplements should be taken with food to prevent gastrointestinal side effects. Fish oil is a blood thinner in some individuals at higher doses (several grams = 2000-3000 mg or higher), so be careful in combining it with other blood thinning medications and do not take it at least 1 week before surgery, and talk with the doctor that you trust the most with your health about whether or not you should even take this stuff. Fish oil is FDA approved to reduce triglycerides, may improve HDL, slightly lower blood pressure, and inflammatory markers (which is how it may reduce stones and muscle loss and battle prostate disease). Fish oil supplements are usually derived from anchovies and sardines (small fish) so they are low in mercury. Those that cannot swallow fish oil pills should aim for 2 fatty/oily fish (anchovies, herring, mackerel, salmon, sardines, trout, tuna, etc.) meals per week (American Heart Association recommendations), which is about the equivalent of 1 fish oil pill per day.

Hold the phone! What about plant sources of omega-3 fatty acids! Yes, many studies are now showing the benefits of plant omega-3 fatty acids and these can get converted into fish oil by the human body. For example, I am a big fan of Chia seeds lately because they are so high in fiber and plant omega-3 fatty acids. It is interesting that another recent large Harvard study of women just showed that these plant omega-3 may reduce the risk of clinical depression and other new studies are suggesting bone healthy benefits as well.

197) Low-dose aspirin for some types of aggressive cancer? Maybe.

(References: Siener R, et al. J Urol 2011;185:719-724; Murphy RA, et al. Cancer 2011, published on-line early. Murphy RA, et al. Cancer, 2011-published on-line early-second article in the same issue; Szymanski KM, et al. Am J Clin Nutr 2010)

BOTTOM LINE:

Low-dose baby aspirin continues to show that it may reduce the risk of being diagnosed with and/or dying from colon and perhaps some other types of gastrointestinal cancers, but whether or not it prevents aggressive prostate cancer from growing is still controversial, but getting more interesting every year.

(Reference: Rothwell PM, et al. Lancet, 2011;377:31-41.)

WHAT ELSE?

Aspirin has to be the most misunderstood over the counter (OTC) product I have ever watched people struggle with over time. It is as confusing as any dietary supplement that you could get your hands on at the local store. Aspirin seems natural because it originally came from willow bark, is dirt cheap, easy to take and it is touted as a miracle drug, so why not have everyone take it? No! (did you just see that exclamation mark? It means that I am very serious here). Aspirin can also cause serious internal bleeding and ulcers (not fun stuff friends). Therefore, aspirin comes with good things for those that qualify and really bad things for those that do not qualify for it. The doctor that you trust the most, and you, should decide if you qualify for a daily aspirin to reduce your risk of cardiovascular disease. In the meantime, take a look at www.reynoldsriskscore.org to help determine your cardiac risk and whether aspirin could provide a benefit. In order to benefit from this wonderful web site you have to know your health numbers/health history and also the result of a newer cheap blood test known as "hs-CRP" (ask your doc to get it with your next cholesterol test and PSA test).

Please keep in mind that by reducing your cholesterol, blood pressure, and not smoking that it can reduce your risk of cardiovascular disease to such an extent that you may no longer qualify for regular aspirin use. Now let's cover the cancer part. There is some recent evidence that individuals may also reduce their risk of dying from cancer if they can take low-dose aspirin for many years (especially 5 or more years). It should be kept in mind that most of these positive studies center around reducing the risk of gastrointestinal cancers (like colon cancer). So, if you are at a high risk for colorectal cancer or have been diagnosed and treated for colorectal cancer you should consider taking aspirin. And, this new analysis of past studies also suggests that aspirin may reduce the risk of dying from prostate cancer. I believe that men with more aggressive prostate cancer (high Gleason scores) should consider taking a baby aspirin daily, if your doctor thinks the benefit would outweigh the risks. This is because aspirin (like statin or cholesterol lowering drugs) appears to have an impact on more aggressive tumors as opposed to non-aggressive tumors. No greater benefits seemed to be observed for those individuals taking more than a baby aspirin. Baby aspirin may keep the prostate cancer away, but if you are not careful and do not carefully weigh the benefits versus the risks…well an aspirin a day could put you in the emergency room or hospital. Take your time and talk to your doctor about the latest research on aspirin and whether or not adding it to your prostate cancer treatment makes sense. Do not make this decision quickly because aspirin can help some folks and damage other folks!

198 & 199) A plethora (or cornucopia) of new studies from Johns Hopkins are a reminder that you should keep your cholesterol and weight at a healthy level after prostate cancer treatment, and do not smoke!

(References: Joshu CE, et al. Cancer Prev Res 2011;4:544-551; Mondul AM, et al. J Urol 2011;185:1268-1273; and J Natl Cancer Inst 2011, April 15 on-line)

BOTTOM LINE:

Heart healthy = Prostate Healthy! Healthy cholesterol, weight, and not smoking can reduce the risk of prostate cancer returning after treatment.

WHAT ELSE?

There is really not much else I can say here, but feel free to look up these studies because these researchers continue to provide really important information that can help you get the most out of your treatment. If I had a penny for every time I met a man that had high cholesterol after surgery or radiation or gained a lot of weight after treatment or continued to smoke I would have enough pennies to keep the Vegas slot machines busy for a few days. Speaking of Vegas, it makes no sense to me to bet on any treatment for prostate cancer unless a man is committed to heart healthy behavior after the treatment. In other words, what was the point of being treated for prostate cancer if other major risks to your health are not reduced after you are treated? It would be like a guy that believes in wearing his seat belt (not the seat belt analogy again Dr. Moyad) every single time he gets into any car because he is convinced it can save his life, but also smoking while he was wearing that seat belt! What?! I almost wish (now for all you politically correct folks this is a make believe comment coming) that every prostate surgeon would refuse to treat men with surgery unless they sign a contract that says that the patient will absolutely try his very best to reduce his risk of cardiovascular disease (CVD) right after surgery! Of course that is not going to happen, except maybe with the new health care plan, it may already be written in there (who knows).

THAT IS ALL FOLKS!

See you in the Fall when we will write about more exciting things such as how the Michigan Football team will surprise everyone in late 2011 and finally beat Ohio State (so I can stop paying for therapy and Ohio State can stop getting paid for selling Big Ten rings…ouch! Rim shot please! I will being doing stand up all year folks! Don't forget to tip your servers!). We will also talk about other serious issues in the next newsletter such as why it is never smart to wear your most expensive dress shoes while walking behind a horse in Central Park that just ate a lot of beans and grass for lunch!

BLADDER MANAGEMENT AFTER PROSTATE CANCER TREATMENT

CANCER BACKGROUND

According to the American Cancer Society, "half of all men and one-third of all women in the US will develop cancer during their lifetimes."[1] However, maintaining a healthy lifestyle and properly screening yourself are two of the best ways to manage your cancer risk.

Years ago, receiving a cancer diagnosis was considered a death sentence. This is no longer the case. Today there are over 11 million people living in the U.S. who have, or have had some type of cancer.[1]

Prostate cancer is the second most frequent type of cancer among American men.[2] One in six men will get prostate cancer at sometime during their life.[2] Today, there are approximately two million men in the United States who have had prostate cancer.[2]

BLADDER CONTROL AND PROSTATE CANCER

Urinary incontinence, which is the loss of urine control, is a common side effect for men who have undergone radiation, or had surgery for prostate cancer.[3] If you will be undergoing treatment for prostate cancer in the near future, you should know it is possible that you will have urinary incontinence, either temporary or permanent.[3]

About 25 million people in the U.S. have some type of urinary incontinence.[4] Therefore if you or someone you know is dealing with incontinence issues it's important to realize you are not alone.[4] Recent estimates by the National Institute of Health (NIH) suggest that 17 percent of men over age 60, an

estimated 600,000 men, experience urinary incontinence, with this percentage increasing with age.[5] Urinary incontinence in women is more common and frequently experienced starting at a younger age. As of age 60, up to 27 percent of the female population experiences urinary incontinence at least once a week.[6]

Many of the men affected by incontinence can attribute their bladder issues to prostate cancer surgery.[4] It is estimated that about half of men who undergo prostate removal surgery will have some bladder leakage.[4] This is most common during the six months following surgery; however 20% of men continue to experience leakage more than a year after surgery.[4]

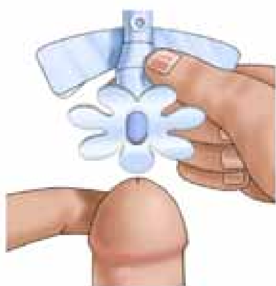
THE RIGHT DOCTOR

If you are currently experiencing urine leakage, or have recently been diagnosed with prostate cancer, be sure to discuss your health concerns with your doctor. But don't be surprised if your doctor is not as knowledgable on new options for managing incontinence as you might think. Because doctors are inundated with treatment information, often they must focus on acute medical conditions. Longer-term maintenance issues can be overlooked. If you learn about a new advancement in urine control, share the information with your doctor!

Also be sure to ask the correct physician: A general practice physician is a good place to start; however, an urologist is more likely to know about new developments in incontinence care.

OPTIONS FOR BLADDER MANAGEMENT

For men managing incontinence, the options are absorbent pads, urethral, suprapubic or intermittent catheters, condom catheters or, the newest technology, the Liberty3.0™ external continence device. Below are images of current male bladder management options.



LIBERTY 3.0

FOLEY CATHETER

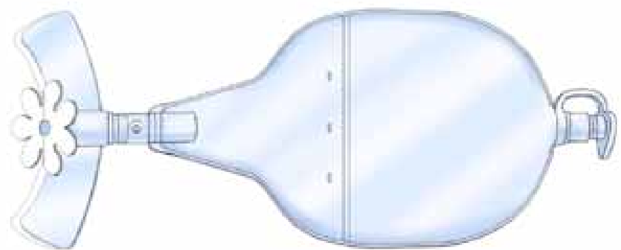
ADULT DIAPER

CONDOM CATHETER

Liberty3.0 is an external continence device for men that seals directly to the tip of the anatomy, directing all urine away from the body and into an integral collection chamber. With a secure seal lasting 24-72 hours, Liberty3.0 is a non-invasive, no-fuss option for urine management.

In response to ongoing customer feedback and testing, Liberty3.0 has recently introduced significant product improvements, including:

- A new 7 petal faceplate design which increases surface area coverage and ease of application
- ExtraDerm™, an improved hydrocolloid adhesive that increases wear time
- An improved BioPlus+™ prep wipe to increase wear time
- FreeDerm™ adhesive remover. This gentle, no-sting wipe increases ease of removal for all hydrocolloid products.



IMPROVED LIBERTY3.0 WITH NEW 7 PETAL FACEPLATE

IMPROVED BIOPLUS™ BARRIER FILM WIPE – IMPROVES ADHESION OF LIBERTY3.0

NEW FREEDERM™ GENTLE ADHESIVE REMOVER WIPE – FOR EASY REMOVAL

These enhancements significantly improve the wear time and ease of use for Liberty3.0!

BENEFITS OF LIBERTY3.0

- Liberty3.0 is designed to fit all male anatomy, including large, small, retracted, and uncircumcised.
- The average reported wear time per Liberty3.0 device is 24 to 72 hours.

- Liberty3.0 users may experience reduced risk for urinary tract infections (UTI), compared to the alternatives. After one million applications there are no reported cases of UTI's caused by Liberty3.0.
- Liberty3.0 users can avoid skin break down, pop offs, urinary tract infections and social isolation caused by other bladder management options
- Liberty3.0 is covered by Medicare, Medicaid, Workers Compensation, the VA and most private insurance plans. Most users pay little to nothing out of pocket.

TRYING LIBERTY3.0

To help men try Liberty3.0, BioDerm provides a free starter pack, which includes four free samples as well as a detailed application DVD. BioDerm's Customer Care team is available to answer all your questions and help you have the best chance of getting the results you desire from Liberty3.0.

For more information on Liberty3.0 and male bladder management, call BioDerm at (800) 373-7006, email us at CustomerCare@BioDerm.us or visit us online at www.bioderm.us.

ABOUT BIODERM

BioDerm, Inc. was founded in1990 to develop unique solutions for long-standing healthcare challenges that affect millions of people. The company's products for urine control, wound care and infection control are based on an innovative hydrocolloid technology that seals securely to skin, providing protection from moisture and bacteria. BioDerm's flagship product is the Liberty3.0 external male continence device, the first new product for men's urine control in 50 years. Liberty3.0 was developed to provide more freedom for men seeking a better method of bladder control and aims to make urinary output monitoring and management healthier and more comfortable. BioDerm is based in Largo, FL. For more information, visit www.BioDerm.us or call (800) 373-7006.

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5. Lynn Stothers, L., Thom, D., Calhoun, E., "Chapter 6: Urinary Incontinence in Men," *Urologic Diseases in America Report 2007,*National Institutes of Health.
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CARING FOR YOUR BONES WHEN YOU HAVE PROSTATE CANCER

BY SUSAN F. SLOVIN, MD, PHD

As we age, we are constantly reminded that we will be experiencing a variety of aches and pains consistent with aging and osteoarthritis. Men with prostate cancer face an additional challenge – keeping bones that may have been weakened by age and inactivity, as well as the cancer itself, healthy.

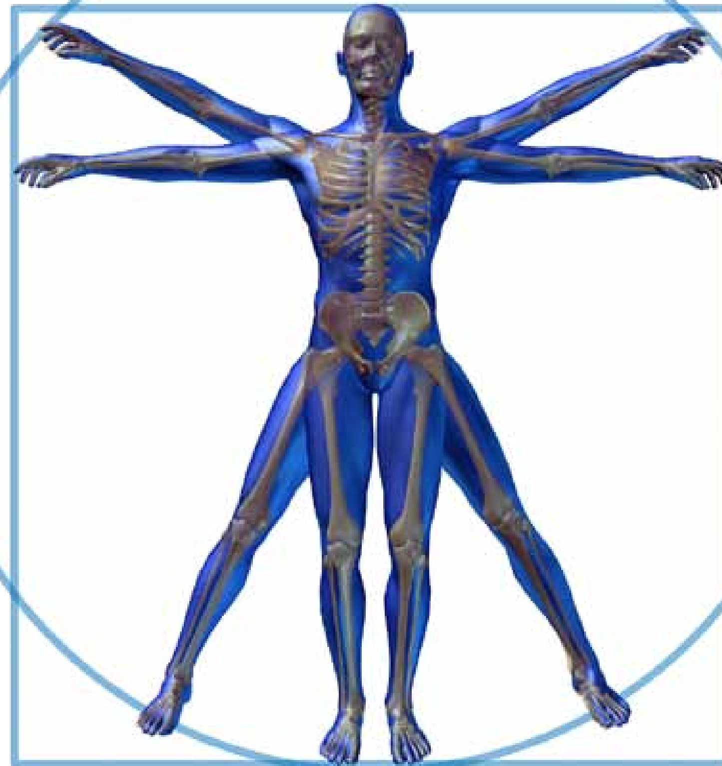
Men with prostate cancer are living longer, which means that future bone complications can occur. These complications include compression fractures, bone weakness due to metastatic cancer, and cord compression (where disease destroys the bone and puts pressure on the spinal cord below). Interventions are needed to prevent these potentially painful conditions.

MONITORING BONE DISEASE

Contrary to what some people believe, men who develop metastatic prostate cancer in their bones may live for years. It is not true that all men develop significant pain. Sometimes, bone pain may be the result of arthritis, osteoporosis, or sports activities, not cancer. Causes of bone loss include a diet low in calcium and vitamin D; poor sun exposure; prolonged bed rest; lack of physical activity; and certain medications, such as anti-convulsants

and prostate cancer therapies like the hormones leuprolide (Lupron™) and goserelin (Zoladex™).

Bone disease may be benign (osteoporosis, osteopenia) or malignant (metastatic cancer). To find out exactly what is causing bone pain, a variety of imaging studies are used. One test that is used to measure bone density is a type of X-ray called the DEXA scan (or Dual Energy Absorptiometry). This test can help your doctor determine whether you need to take calcium and/or vitamin D supplements. A simple urine test can also measure bone loss.



Standard imaging tests can also be used to test for osteoporosis. A CT (computerized tomography) scan can be focused on the lower back, a site where men are more likely to experience osteoporosis. Another method used to assess changes in the bone is MRI (magnetic resonance imaging), which uses magnetism, radio waves, and a computer to produce detailed images of bony structures.

TREATING BONE DISEASE AND PAIN

When bones are weakened by cancer, they may easily break with a fall or injury. Bones may also spontaneously break without any injury or symptoms other than some mild discomfort. Treatment for bone loss may include a group of compounds known as bisphosphonates, which prevent special bone cells (osteoclasts) from destroying existing bone and weakening it. Zoledronic acid (Zometa™) is one example of a bisphosphonate. This drug is indicated mainly for men with prostate cancer. Another medication in this class of drugs is Alendronate (Fosamax™), but it is used for osteoporosis, not prostate cancer.

Bisphosphonates are FDA approved for a variety of different malignancies. However, a rare side effect of this type of drug is osteonecrosis of the jaw (ONJ), which presents as a heaviness in the jaw, pain, or swelling or infection of the gums. If you are taking a bisphosphonate, you should inform your dentist so that you can be monitored for ONJ.

When a person experiences bone pain in the setting of known bone metastasis, there is obvious concern that the pain may be a symptom of cancer spreading. However, there are other, more common, reasons for bone pain. When in doubt, scans should be performed to assess the status of the bone disease. When bone pain is not a result of cancer metastasis, pain medications (acetaminophen, non-steroid anti-inflammatory drugs like ibuprofen) can be given for mild to moderate pain. If pain is more severe, either short-acting or long-acting opiates can be given.

PROMOTING BONE HEALTH

You should try to eat plenty of low-fat dairy products; dark, leafy greens; and fatty fish, such as tuna, salmon, sardines, herring, mackerel, and swordfish. Sun exposure also has importance, but excess sun exposure should be avoided. You may also want to talk to your physician about whether you should take calcium and/ or vitamin D supplements.

If you are able, light exercise should be part of your plan to maintain bone health. Exercise maintains bone strength and reduces the loss of calcium in your bones. Weight-bearing activities such as walking, swimming, dancing, stair-climbing, or light weightlifting promote bone strengthening by stressing bones naturally. In addition, greater muscle strength from exercise ensures better coordination so that falls can be avoided and injuries to bones can be lessened.

Remember, the purpose of cancer treatment is to not only control your cancer but also maintain your quality of life. Maintaining the health of your bones is an important component of ensuring a good quality of life.

Dr. Susan Slovin is associate attending physician at the Sidney Kimmel Center for Prostate and Urologic Cancers and Memorial Sloan-Kettering Cancer Center and associate professor of Medicine at Weill-Cornell Medical College in New York.

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CHANGING YOUR LIFESTYLE CAN CHANGE YOUR GENES

By Dean Ornish M.D.

New research shows that improved diet, meditation and other non-medical interventions can actually "turn off" the disease-promoting process in men with prostate cancer.

Here's some very good news: your genes are not your destiny. Earlier this week, my colleagues and I published the first study showing that improved nutrition, stress management techniques, walking, and psychosocial support actually changed the expression of over 500 genes in men with early-stage prostate cancer. This study was conducted at the non-profit Preventive Medicine Research Institute and the University of California, San Francisco in collaboration with Dr. Peter Carroll, Dr. Mark Magbanua, Dr. Chris Haqq, and others.

In this study, published in the Proceedings of the National Academy of Sciences, we studied gene expression in biopsies from 30 men who were diagnosed with low-risk prostate cancer. These men had decided not to undergo conventional treatments such as surgery, radiation, or chemotherapy for reasons unrelated to the study. They had early, small-volume prostate cancer with stable prostate specific antigen (PSA) levels and Gleason scores of six or less, meaning that their tumors were not aggressive.

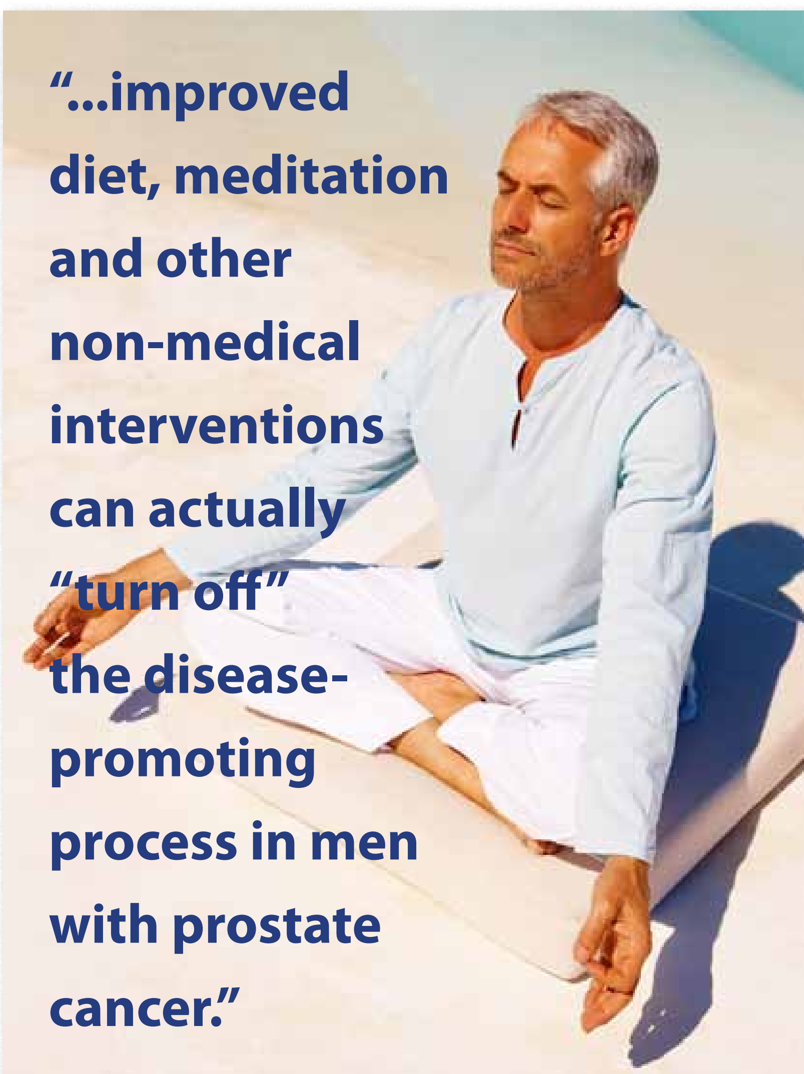
> "We showed that comprehensive lifestyle changes may stop or reverse the progression of coronary heart disease, diabetes, hypertension, obesity, hypercholesterolemia, and other chronic conditions."

We biopsied their prostates at the beginning of the study and again three months later, after making comprehensive lifestyle changes. Since these patients did not have conventional treatments during this time, it enabled us to assess the effects of the lifestyle changes on gene expression without confounding interventions such as surgery, radiation, or chemotherapy.

The changes included a plant-based diet (predominant fruits, vegetables, legumes, soy products, and whole grains low in refined carbohydrates), moderate exercise (walking 30 minutes per day), stress management techniques (yoga-based stretching, breathing techniques, meditation, and guided imagery for one hour per day), and participating in a weekly one-hour support group. The diet

was supplemented with soy, fish oil (three grams/day), vitamin E (100 units/day), selenium (200 mg/day), and vitamin C (2 grams/day). These lifestyle changes are described more fully in my book, *The Spectrum*.

After three months, we repeated the biopsy and looked at changes in normal tissue within the prostate. We found that many disease-promoting genes (including those associated with cancer, heart disease, and inflammation) were down-regulated or "turned off," whereas protective, disease-preventing genes were up-regulated or "turned on." For example, a set of cancer-promoting oncogenes called RAS was down-regulated in these men. The Selectin E gene (which promotes inflammation and is elevated in breast cancer) was down-regulated. Another gene that suppresses tumor formation called SFRP was up-regulated, thereby reducing the risk of cancer. These genes are the target of many new drugs that are being developed. Clearly, changing lifestyle is less expensive, and the only side-effects are good ones. Dr. Craig Venter's pioneering research is showing that one way to change your genes is to synthesize new ones. Another may be to change your lifestyle.



For the past 31 years, I have directed a series of research studies showing that changes in lifestyle can make a powerful difference in our health and well-being, and how quickly these changes may occur. We showed that comprehensive lifestyle changes may stop or reverse the progression of coronary heart disease, diabetes, hypertension, obesity, hypercholesterolemia, and other chronic conditions.

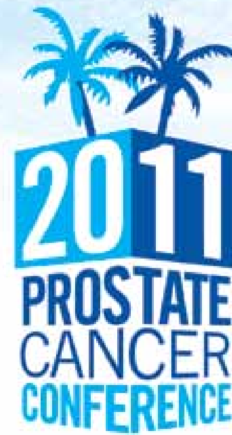
Two years ago, along with Dr. Carroll (Chair of Urology, UCSF) and others who also collaborated on the new gene expression study, we published the first randomized controlled trial showing that these lifestyle changes may slow, stop, or even reverse the progression of prostate cancer, which may affect breast cancer as well. When we published our earlier studies, we didn't understand many of the mechanisms by which these changes may have occurred. Now, our new study is beginning to provide some insight into what some of these genetic mechanisms may be.

Because we looked at normal tissue within the prostate (rather than the prostate tumor cells), it is likely that our findings may be generalized beyond men with prostate cancer. Also, people who are otherwise healthy may not need to make such intensive changes and have a spectrum of choices. We are still trying to understand the full significance of these findings--we've raised more questions than we've answered, and we need larger, longer-term studies--but it's already clear that you may be able to alter, at least to some degree, how your genes are expressed simply by changing your diet and lifestyle.

I find this to be a profoundly hopeful message. Often, I hear people say, "Oh, I've got bad genes, there's nothing I can do about it"--displaying what I call genetic nihilism. Our findings (the first to show the effect of lifestyle changes on any kind of cancer genes) can be an antidote to genetic nihilism and, I hope, motivate people to begin making their own changes. In most cases, our genes are only a predisposition; they are not written in stone. And if we have a strong family history for diseases such as prostate cancer, breast cancer, or heart disease-- "bad genes"-- then we may need to make bigger changes in lifestyle in order to help prevent or even reverse chronic diseases. In the centuries-old debate about nature vs. nurture, we are learning that nurture affects nature as much as nature affects nurture. It's not all in our genes.

MEDICARE TO PAY FOR CANCER DRUG

WASHINGTON – Medicare officials said Wednesday, March 30th, 2011, that the program will pay the $93,000 cost of prostate cancer drug Provenge, an innovative therapy that typically gives men suffering from the disease an extra four months to live. The Centers for Medicare and Medicaid said the biotech drug made by Dendreon Corp. is a "reasonable and necessary" medicine. The decision ensures that millions of men would be able to afford the drug through the government-backed health care coverage. With government reimbursement, the analysts estimate Provenge could rack up $1 billion in sales next year. The decision will be finalized by June 30. Medicare cannot consider price when deciding whether to pay for a new treatment.



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We are pleased to announce the 13th major conference devoted to prostate cancer, planned and/or produced by members of The Prostate Cancer Research Institute.

CONFERENCE HIGHLIGHTS

Again this year, the conference will be moderated by Dr. Mark Moyad. The conference agenda will deal with topics ranging from Active Surveillance and Nutrition through treatment of advanced disease.

YOU ASKED FOR MORE!

This year, we are adding some introductory sessions late Friday afternoon to allow early arrivals, especially those new to the conference, to prepare for the main sessions. Watch for details.

We will also add talks on Sunday morning with the Expert sessions and Round Table moved to after lunch.

MEET THE SPEAKERS

After speakers present, attendees will have the opportunity to meet the faculty and ask questions.

AND MUCH, MUCH MORE!

REGISTRATION FEE*

Early (through June 15th) $60
Regular (through Sept 8th) $120
On-site $150

OPTIONAL

Saturday Gala Dinner $50
Friday Hollywood Bowl $50
Sunday Sunset Dinner Cruise in Marina del Rey $80

*Registration fee includes access to conference and support group meetings. Hotels, meals, taxes, & gratuities are the responsibility of each attendee.

TO REGISTER BY PHONE, CALL 310-743-2117

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New Mexico..........1
New York..............8
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S Carolina..............1
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Virginia..................3
Washington...........3
Wisconsin..............3

FINANCIAL SUMMARY REPORT
(JANUARY 1, 2010 THROUGH MARCH 31, 2011)

	GENERAL FUND
Balance on Hand December 31, 2009	1,680,280.68
REVENUES RECEIVED -	
Membership Contributions	19,626.67
Memorial Income	2,565.00
Trusts & Bequests	0.00
Investment Income	9,520.20
Miscellaneous Income	0.00
Total Revenues	31,711.87
Total Balance on Hand and Revenues	1,711,992.55
EXPENDITURES-	
Investment Withholding	0.00
Employee Wages	24,785.88
Payroll Taxes	2,244.45
Insurance (Health, House, Workman's Compensation)	9,001.29
Outside Services, Labor	2,677.50
Rent	3,750.00
Meals, Motel, and Transportation	1,136.41
Auto Expense	430.00
Printing	5,376.49
Postage and Delivery	6,245.85
Telephone	1,610.41
Service Plans/Licenses & Permits	2,424.53
Program Expense-Conference Exhibit Fees	625.00
Office and Computer Supplies	341.56
Utilities - Refuse	0.00
Repairs (Building, Equipment)	665.47
Miscellaneous	237.04
Total Expenditures	61,551.88
Balance on Hand March 31, 2010	1,650,440.67
Assets:	
Checking Account	4,838.26
Petty Cash	50.00
Savings Account	29.63
Certificates of Deposit, Stocks, and Bonds	1,302,292.69
Money Market Funds	240,782.18
Equipment	13,338.06
Net Assets:	1,561,330.82
Foundation Fund Balance:	286,651.40

CHOICES

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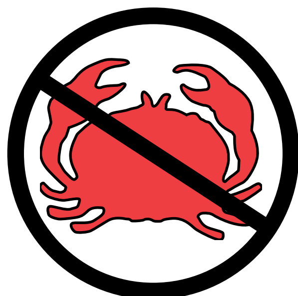

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