

## My Prostate Cancer Experience and Lessons Learned

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### My Experience

In **January 2002** at age 69, I learned that I had prostate cancer. The two right of four biopsy samples collected by Dr. David Noller, an urologist in San Jose, CA, were positive. The Gleason score was 4+4=8 (verified by Johns Hopkins University) and the stage was T1c. My PSA was 6.4 with 17% free. CT and bone scans were negative. The size of my prostate was 64 cc. (In January 1999, my PSA was 4.5, and a concomitant biopsy was negative.)

I may have had a genetic predisposition for prostate cancer as my father was diagnosed with it at age 80 in 1971, and died from the disease in 1977 at age 86. However, my 3 older brothers (15-years older (deceased at age 89), 13-years older, and 5-years older) and my father's brother (deceased at age 70) haven't, or hadn't, been diagnosed with prostate cancer. Also my mother, her sisters, and my father's sisters hadn't been diagnosed with breast cancer.

Dr. Noller recommended radioactive seed implants and I met with Dr. Stephen Kurtzman, a radiological oncologist, who would perform the implants and whom Dr. Noller would assist. I got a second opinion from Dr. Scott Angel, an urologist in Mountain View, CA, who recommended surgery. I did some research, mostly via the Internet. Unfortunately I did not become aware of the Partin Tables and the high probability of recurrence associated with my PSA and Gleason score, and no one suggested that I attend a prostate cancer support group.

Mistakenly, I felt pressured (mostly self imposed) to do something as soon as possible and had radioactive seeds implanted in **August 2002**. (With 20/20 hindsight, I should have taken more time and done much more research.) For 6 months prior to the implants, I had Lupron shots to shrink my prostate down to about 40 cc; the only side effect was loss of libido.

The rectal ultrasound probe probably bruised my colon during the implant procedure, as I had moderately severe rectal pain for a couple of weeks when a stool filled the lower colon. I also had a very severe hemorrhoid attack within a week or two of getting the implants. A few weeks after the implants I started experiencing difficulty urinating. I had trouble initiating urination, my stream was weak and intermittent, and I had some burning during urination. These problems peaked in a couple of months and then subsided; I never needed catheterization. By January 2003 I was essentially back to normal.

My PSA in **April 2003** was 0.1. In 2005 my PSA began rising and I started getting a PSA check every 3 months instead of once a year. In **February 2006**, a Prostatecint scan showed activity in the prostate bed (in or near the prostate), but a concomitant 12-sample biopsy by Dr. Noller was negative. Dr. Noller recommended hormone blockade. When I said that I would get second opinions, he said I'd get as many opinions as doctors I consulted. He was correct.

By **September 2006** my PSA was 8.73 with about a 3-month doubling time.

From **September through December 2006**, I went to the comprehensive cancer centers at Stanford University, UC San Francisco (UCSF), Memorial Sloan Kettering (MSK) in New York City, and Johns Hopkins University (JHU) in Baltimore.

In **September 2006** I met with Drs. Sandhya Srinivas, a medical oncologist, and Christopher King, a radiation oncologist, at Stanford. They recommended hormone blockade (they didn't specify whether it should be single, double, or triple) and that I get CT and bone scans. Dr. Noller considered the scans superfluous, but I had them performed and they were negative.

In **October 2006** I learned about the benefit of pomegranate juice for prostate cancer and started drinking 8 oz daily.

In **October 2006** I met with Dr. Mack Roach III, a radiation oncologist at UCSF. He recommended IMRT (Intensity Modulated Radiation Therapy) if my cancer was localized, and he ordered an MRSI (MRI with spectroscopy) to determine if it was. The MRSI, performed at UCSF in **November 2006**, showed an anomaly in the prostate. A follow up biopsy was scheduled for **January 2007**.

In **November 2006** I met with Dr. Lewis Kampel, a medical oncologist at MSK, who recommended hormone blockade (he didn't specify what type) and consideration of salvage surgery if the MRSI showed that my cancer was localized.

In **December 2006** I met with Dr. Charles Drake, a medical oncologist at JHU, who recommended hormone blockade (he didn't specify what type) and consideration of IMRT if the MRSI showed that my cancer was localized.

I asked Dr. Drake for recommendations about diet, and he gave me a paper published in 2004 about a clinical trial applying the Dean Ornish Lifestyle Program to prostate cancer patients. The Program is a restricted vegan diet, exercise, meditation, and participation in a support group. The trial results were impressive, and some research that I did supported those results. I started the diet in **late December 2007** and used FitDay.com to keep a daily log of what I ate.

Dr. Drake, Dr. Noller, and my niece (a surgical nurse at Baltimore's shock trauma center) strongly recommended against salvage surgery, as it would be very difficult and risky due to the scar tissue in the prostate bed from the radiation. Uncontrollable bleeding can occur and patients have bled to death on the operating table.

In **December 2006** my PSA dropped to 7.98. This may have been due to the pomegranate juice that I started taking in October as nothing else in my regimen had changed.

In **January 2007** a 21-sample biopsy, performed by Dr. Katsuto Shinohara at UCSF as a follow up to the MRSI, was negative. This meant that the cancer probably wasn't localized and I probably had micro metastases of prostate cancer too small to detect. Following this biopsy I had difficulty urinating plus an urgency problem. The biopsy probably caused inflammation and edema, and a sphincter muscle may have been damaged. Many months later these problems had substantially subsided. Currently I have an occasional, slight urgency problem but little difficulty urinating.

In **January 2007** I met with Dr. Toby Morris, a registered dietician at UCSF. She provided guidance on how to comply with the Dean Ornish diet. She also urged me to meditate and attend a support group.

Although each of the cancer centers made different recommendations, they all recommended hormone blockade if the cancer was not localized. In **February 2007** based on

recommendations by Drs. Noller and Roach, I started a double hormone blockade with monthly shots of Lupron (7.5 mg) and a daily pill of Casodex (50 mg).

I now know that I didn't have a complete, balanced picture yet, and that the recommendations I'd received so far were incomplete and portions were incorrect. However, I'm sure that each doctor believed that his or her recommendations were complete and correct for me.

In **April 2007** through my online research, I learned of Dr. Charles E. "Snuffy" Myers who is located in Earlysville (near Charlottesville), Virginia. Dr. Myers was a prostate cancer research medical oncologist and Director of the Cancer Center at the University of Virginia when he was diagnosed with aggressive, metastatic prostate cancer in 1999 at age 55. He consulted with the leading experts in each aspect of his disease, decided what the best treatment was for each aspect, got and has kept his cancer in remission, and now runs his own prostate clinic. Partly due to the vested interest in his own disease, he stays aware of the latest developments in all aspects of prostate cancer. After reading his book (Beating Prostate Cancer: Hormone Therapy and Diet), I asked Dr. Noller to add a daily pill of 0.5 mg Avodart to my regimen thus putting me on a triple hormone blockade. I also asked him to increase my Casodex to 3 pills (150 mg) per day.

I subsequently met with Dr. Roach who recommended that I see a medical oncologist at UCSF since my prostate cancer couldn't be localized. He also told me to only take one Casodex per day because the FDA had rejected a request to approve 3 per day; I changed to one per day.

I met with Greta Macaire, a registered dietician at the UCSF Comprehensive Cancer Center. She provided information about foods and supplements beneficial or detrimental for prostate cancer, and additional guidance regarding the Dean Ornish diet.

About this time I finally started participating in a meditation group and going to a prostate cancer support group (I should have started when I was first diagnosed with prostate cancer).

In **May 2007** I met with Dr. Myers. He recommended a color Doppler ultrasound by Dr. Duke Bahn in Ventura, CA as well as some changes in my diet (switch to a Mediterranean diet) and supplements (add lycopene, omega-3 fish oil, selenium, soy isoflavones, vitamin B6, vitamin D3, & vitamin E and substitute pomegranate extract for pomegranate juice due to the sugar content of the latter).

I met with Dr. Drake at JHU a few days later and he agreed with Dr. Myers recommendations.

In **June 2007**, the color Doppler ultrasound by Dr. Bahn also showed an anomaly in the prostate, but a concomitant 9-sample biopsy was negative.

In late **June 2007** I met with Dr. Charles J. Ryan, a medical oncologist at UCSF. He recommended that I stop taking Avodart saying it had negligible benefit for prostate cancer. In **July 2007** I met with Dr. Amy M. Lin, a medical oncologist at UCSF. She concurred with Dr. Ryan's recommendation. I did not change my regimen.

In **September 2007**, I attended the Prostate Cancer Research Institute 2007 National Conference on Prostate Cancer. Over 2-1/2 days leading experts in many aspects of prostate cancer made outstanding presentations. Both my wife Peggy and I felt that those presentations confirmed my treatment regimen. (We also went to the 2008 National Conference on Prostate Cancer and it was equally outstanding.)

In **September 2007**, Dr. Myers recommended that I get monthly checks of my testosterone, dihydrotestosterone, and 25-hydroxy-vitamin-D levels in addition to my PSA level. (I should

have started having these parameters measured in February 2007 when I first started my hormone blockade treatment.)

In **October 2007**, Dr. Myers said that my PSA was not dropping fast enough and he increased my dose of Casodex to 150 mg per day.

In **November 2007** I again met with Greta Macaire who provided additional information about which foods and supplements are beneficial or detrimental for prostate cancer patients.

In **January 2008**, I met with Dr. Aaron Katz, a urologic oncologist and head of the Urologic Holistic Center at Columbia University Medical Center. He concurred with my treatment regimen.

In **April 2008**, I met with Dr. Peter Yu, a medical oncologist in Mountain View, CA. Dr. Myers said I needed a local oncologist with whom he could work. Dr. Yu agreed to do that.

In **May 2008**, Dr. Myers said that my PSA was not dropping fast enough and prescribed Vivelle DOT patches (Estradiol) and Cabergoline (to suppress breast enlargement).

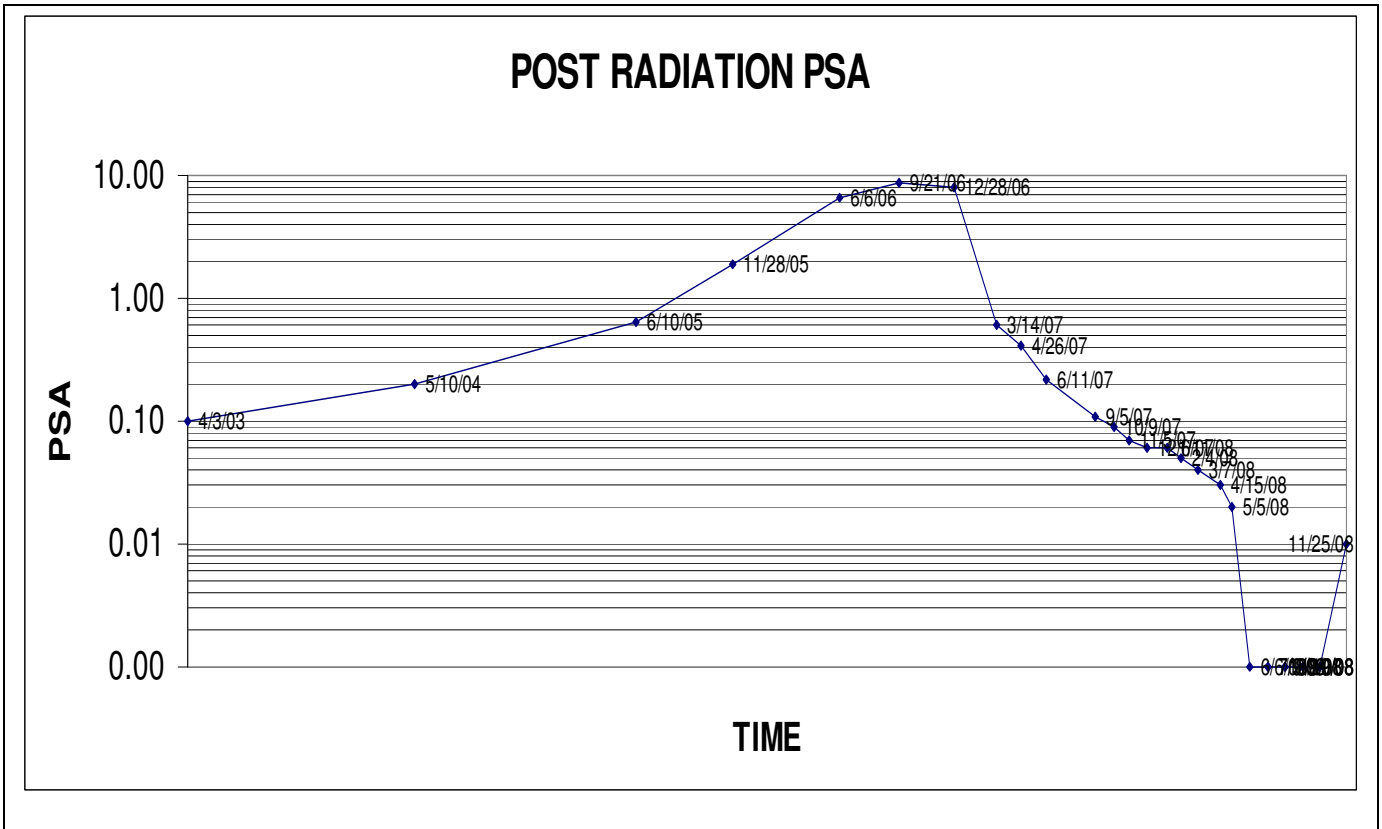
In **early June 2008** my PSA was less than 0.01 (i.e., undetectable). In **mid June 2008** Dr. Myers said I could stop the Lupron and Casodex. In **late June 2008** I met with Dr. Myers who said that I should continue the Estradiol patches for 2 more months and then taper off them the 3<sup>rd</sup> month. He recommended that I take 1000 mg/day resveratrol concentrate (the anti-cancer component of red wine) and 1000 mg/day quercetin (prevents the liver from destroying the resveratrol) to my supplement regimen. A few days later I met with Dr. Drake of JHU who concurred with Dr. Myers recommendations.

In **July 2008** I met with Greta Macaire who provided additional guidance about the foods I eat and supplements I take.

In **August 2008** I stopped the Estradiol skin patches and the Cabergoline.

My PSA continued to be less than 0.01 (undetectable) through **October 2008**. However, my PSA was 0.01 in **November 2008** and 0.02 in **December 2008** and **January 2009**.

My current treatment regimen is Avodart plus several supplements (see Appendix A), a restricted Mediterranean diet (see Appendix B), an exercise program (walking, weight training and stretching), meditation, and active participation at three prostate cancer support groups.



## **Lessons Learned**

The following lessons also generally apply to many other cancers.

**First, get tested regularly** if you are 50 or more years old. If your father or a brother has been diagnosed with prostate cancer, or your mother or a sister has been diagnosed with breast cancer, or you are an African-American, start getting tested at 40 years old. Typically prostate cancer has no symptoms until it reaches an advanced stage when it is much more difficult to treat. Early detection provides the best chance to eradicate the cancer cells and avoid a recurrence. An annual PSA check and an annual DRE (digital rectal exam) currently provide the best means of early detection of prostate cancer (better testing methods are being developed). Also get a testosterone check to establish a base line.

A high PSA doesn't necessarily mean prostate cancer, and a low PSA doesn't rule out prostate cancer. A high PSA can be due to several other causes such as BPH (benign prostate hyperplasia), infection in the prostate, recent sexual activity, recent bicycle riding, a recent digital rectal exam, etc. The rate of change in the PSA is important; a low PSA that is rising can be due to prostate cancer.

A negative biopsy of the prostate doesn't rule out prostate cancer; the cancer can be very small and easily missed by the biopsy needle. A biopsy guided by color Doppler ultrasound is probably the most accurate at this time.

The use of other bio-markers including PAP, NSE, CGA, and CEA (respectively Phosphatic Acid Phosphatase, Neuron specific enolase, Chromogranin A, and Carcinoembryonic Antigen) can be helpful in determining the nature of your prostate cancer and consequently the best treatment for you. (See <http://www.annieappleseedproject.org/twomorpres.html> for more information.)

**Second, keep a personal file of the parameters for your prostate cancer.** These parameters include your PSA, prostate size, the number of biopsy samples, and the number, portion and location of positive samples, Gleason score, stage, and your baseline testosterone level.

Have your PSA checked monthly. If your PSA is below 0.3, get it determined by the ultrasensitive PSA method. If you go on hormone blockade, also have your testosterone and dihydrotestosterone levels checked monthly since the purpose of the blockade is to suppress these hormones. Also have your 25-hydroxy-vitamin-D level checked monthly; it should be between 50 and 100 ng/ml.

Staging determines the extent of prostate cancer. A number of tests such as CT scans, MRIs, x-ray and bone scans can be used to help determine the stage of disease; however, these tests cannot detect small tumors of cancer cells (the threshold for detection is a tumor about 0.5 cm in diameter). Knowing the stage of disease helps to determine how aggressively to treat the disease, and how likely it will be eradicated by the available treatment options.

**Third, go to a cancer support group (a prostate cancer support group if available).** The members are an excellent source of information based on first-hand experience. I now actively participate in three prostate cancer support groups and usually learn something pertinent to my prostate cancer at each meeting; I wish I had gone when I was first diagnosed. If a prostate cancer support group does not exist in your area, start one yourself ([www.USTOO.com](http://www.USTOO.com) provides guidance).

**Fourth, take lots of time to choose the treatment that is best for you.** Dr. David Lee, chief of urology at Penn Presbyterian Medical Center, says, "Take your time to learn all that you can so you can make a good decision."

Depending on your PSA, Gleason score and stage, you have several months to a year to decide, and you can substantially extend that time with hormone blockade therapy. The side effects of hormone blockade therapy are preventable or controllable, and all except breast enlargement are reversible. **Do lots of research. You have to become the expert about your disease and what's best for you.** Prostate cancer is a complicated disease with multiple treatment options, and no single treatment regimen is best for everyone. From the June 2008 issue of *Harvard Men's Health Watch* Newsletter:

To help answer the crucial question of how to best treat prostate cancer, the American Urological Association convened a Prostate Cancer Clinical Guidelines Panel. But after reviewing more than 13,000 studies, the expert panel was unable to establish recommendations. That's because the studies differed substantially in such factors as patient age, disease stage, and follow-up, making direct comparisons impossible. New studies to resolve these issues will not be completed for years.

Until then, patients have to choose for themselves among several acceptable options. The June 2008 issue of *Harvard Men's Health Watch* outlines some general guidelines to help men decide which treatment is best for them. A man must know his cancer's stage and its Gleason score (a ranking that considers the cancer's aggressiveness). But other factors are important, too, including his age, general health, and life expectancy, and the experience and skills of his medical team. And every patient should consider how each treatment—and its side effects—will affect his quality of life.

Most doctors cannot give you complete balanced advice about your prostate cancer, they are knowledgeable about the latest developments in their own specialty, but can't keep up with the latest developments outside their specialty. For example, most surgical oncologists will know the latest in surgery, but not in other areas such as radiation or hormone blockade therapy. Only a few doctors in the U.S. keep abreast of the latest developments in all aspects of prostate cancer.

As mentioned above, a prostate cancer support group, or even a general cancer support group, is an excellent source of information. A hospital library is a good source of information, and librarians love helping you find information. The Internet has lots of good information, but also lots of incorrect information; so check and recheck information you find online. A few web sites that I've found to be useful are: [www.USTOO.com](http://www.USTOO.com), [www.paactusa.org](http://www.paactusa.org), [www.prostate-cancer.org](http://www.prostate-cancer.org) (PCRI), [www.prostateforum.com](http://www.prostateforum.com) (Dr. Charles "Snuffy" Myers), [www.pcref.org](http://www.pcref.org) (Dr. Israel Barken), [www.prostateoncology.com](http://www.prostateoncology.com) (Drs. Mark Sholz, Richard Lam, Duke Bahn), and [www.compassionateoncology.org](http://www.compassionateoncology.org) (Dr. Robert L. Leibowitz). Triple and quadruple check any information in the general news media (TV, newspapers, etc.).

**Fifth, read at least four books:** "Beating Prostate Cancer: Hormone Therapy and Diet" by Dr. Charles E. "Snuffy" Myers, "A Primer on Prostate Cancer" by Dr. Stephen B. Strum (get the 2<sup>nd</sup> edition), "Dr. Patrick Walsh's Guide to Surviving Prostate Cancer" by Patrick Walsh and Janet Worthington (get the 2<sup>nd</sup> edition), and How Doctors Think by Dr. Jerome Groopman. Dr. Myers' book provides a balanced view of prostate cancer treatment options, is very readable, and is upbeat. Dr. Strum's book is a very complete and balanced book, but is a little dry and clinical. Dr. Walsh is a surgeon at Johns Hopkins and has a surgeon's bias, but his book provides an excellent review of prostate cancer basics and is very educational. Dr. Groopman is a

hematologist and oncologist at Harvard Medical School; his book explains how and why doctors make diagnostic errors and what you can do to minimize those errors.

**Sixth, get copies of all records related to your prostate cancer** and keep a meticulous file. This includes records of all lab tests, biopsies, scans, and recommendations and assessments of doctors. Federal law states that you are entitled to them and you will need them when you go for 2<sup>nd</sup> opinions.

**Seventh, find a medical oncologist to be the primary doctor for your prostate cancer** and preferably one that treats only prostate cancer; examples are Dr. Myers and Dr. Strum. My urologist may have recommended radioactive seed implants, at least partly, because of his vested interest in seed implants. Surgeons have a vested interest in surgery; radiologists have a vested interest in radiation therapy; etc. A medical oncologist is less likely to have a vested interest in the treatment that you select.

You should rely on your primary oncologist to make the decisions about your prostate cancer. You should also have one or two secondary oncologists that you use to double check the decisions of the primary oncologist. **If your treatment isn't working or you have good reason to believe that your primary oncologist is not making the best decisions for you, find another primary oncologist.**

**Eighth, a "Gold Standard" treatment is not necessarily the best.** It has the best results of the treatments that have long track records; however, a treatment with a shorter track record might be better for you.

**Ninth, find an "artist," someone who is a leading expert, to perform the treatment that you select.** Your primary oncologist should treat only prostate cancer, and any doctor who performs a procedure (such as surgery or radiation therapy) should have performed hundreds of equivalent procedures with outstanding results.

**Tenth, prostate cancer currently cannot be cured and can recur following any initial treatment.** All treatments, including a radical prostatectomy, leave some untreated prostate tissue in the body. Also there is a significant probability that micro metastases already exist even if all of your scans are negative; the threshold for detection is a concentration with millions of prostate cancer cells. Furthermore, any procedure that physically perturbs the prostate cancer (such as surgery, radiation, or biopsies) might cause the cancer cells to spread. **So, regardless the outcome of your treatment, you must continue to monitor and, as necessary, control your prostate cancer.**

**Eleventh, the best defense against a recurrence is to modify your lifestyle:** avoid red meat protein including dairy protein (it enhances cancer); minimize alcohol, sugar and simple starches (they feed the cancer cells); exercise (it enhances the immune system); meditate (it enhances the immune system); and actively participate in a support group (it enhances the immune system).



**Appendix A – My Prostate Cancer Drug & Supplement List**

<b>Drug</b>	<b>Dosage</b>	<b># per Day</b>
Avodart	0.5 mg	1

<b>Supplement</b>	<b>Dosage (per tablet)</b>	<b># Per Day</b>
Lycopene -----	20 mg-----	3
Omega 3-----	500 mg-----	4
Pomegranate capsules -----	400 mg-----	4
Quercetin -----	500 mg-----	2
Resveratrol -----	500 mg-----	2
Selenium -----	200 mcg-----	1
Soy Isoflavones-----	100 mg-----	2
Vitamin B6-----	50 mg-----	1
Vitamin D3 -----	5000 IU-----	1
Vitamin E -----	200 IU-----	1

**AVOID**

Tylenol

**Appendix B -- My Prostate Cancer (Pesca-Vegan) Diet Guidelines****The Following are Beneficial:**

- Most fruits or vegetables; cabbage family members (broccoli, cauliflower, onions, radishes, horseradish) have been shown to be very beneficial for cancer patients.
- Cold water fish: salmon, haddock, halibut, cod, pink tuna, herring, sardines, and arctic char.
- Egg whites or egg beaters.
- Most nuts: pistachios, almonds, cashews, macadamia, hazelnuts, pine, and pumpkin (in moderation due to high caloric value).
- Olive, avocado, and hazelnut oils (in moderation due to high caloric value).
- Red wine (less than 10 ounces per day due to alcohol and high caloric value).
- Dark chocolate (in moderation due to high caloric value).
- Whole grain bread, brown rice, whole grain pasta, and legumes (in moderation due to high caloric value).
- Get complete proteins by combining rice and tofu, rice and beans, or pasta and beans (they can be eaten at different meals). Seafood, egg whites and soy protein powder are good sources of protein.
- Green tea (6 cups of per day) and grapefruit juice (at least 4 oz per day to facilitate absorption of Avodart).
- Shellfish, flounder, grouper, snapper, white meat chicken, and white meat turkey are all OK although not beneficial.
- Strive for 30% fat, 30% protein, and 40% carbohydrates.
- Eat small meals throughout the day rather than three big meals.
- Achieve and maintain a BMI (body mass index) less than 25.
  - No bell peppers or MSG (I'm allergic).
  - No caffeine after lunchtime (it keeps me awake at night).

**The Following are Detrimental:**

- Most animal protein: red meat (beef, lamb, and pork), all dairy products, egg yolks, and dark meat poultry.
- King mackerel, shark, and albacore tuna (due to the high mercury content).
- Canola, sunflower, flax, and other vegetable oils.
- Miso, peanuts, pecans, and walnuts.
- Juiced carrots (due to the large amount of beta carotene in a glass of juice; however, eating carrots is OK).
- Avoid, to the extent possible, simple carbohydrates such as alcohol, starches, sugar, and honey as they contain lots of calories but little fiber or nutrients.
- Avoid salt to the extent possible.

**One of the side benefits of this diet is that I no longer have GERD and stopped taking Nexium.**