PROSTATE CANCER ADVISORY (Class of '60)

We Class of '60 guys have been running a prostate cancer support group for the past seven years. The idea is to both offer support to the newly diagnosed (been there, done that) and to act as a resource to make more information available for an individual's decision making after being diagnosed with either PC or BPH. We owe a great deal to the Class of '58 for their help in getting our group started. The following guide on prostate cancer prevention was developed by the Class of '58 for their internal use, and has been updated and improved several times over the past several years, and got the mark of approval from their class oncologist. It is pretty darned good and well worth the time to read it. If you want to touch base with our group, email contacts are available in section 2, below.

PROSTATE CANCER PREVENTION AND CONTROL GUIDE

(Revised February, 2010 for use by USMA Classes)

We are all at significant risk for cancer, more so as we age. Our cells are mutating all the time. It comes with the environment replete with a multitude of chemical and radiological carcinogens. It only takes one cell to develop into cancer. The significance to those of us at our stage of life is that as many as half of us in our 70's have latent prostate cancer (PC), the causes of which are not yet fully understood. But there are at least three causative factors: lifestyle choices, genetic propensity and exposure to carcinogens. Fortunately, we all come equipped with an amazing built-in immune system that helps keep latent (histological) cancer from becoming symptomatic (clinical) in any of its many forms. That is unless we fail to maintain that system properly or we allow it to become overwhelmed with more carcinogens than it is designed to handle. And fortunately, while there is still much to learn about PC, we have enough information to know that there is a great deal we can do to decrease the chance that it will ever become symptomatic, despite popular beliefs to the contrary. We can choose to apply that knowledge to modify our diets and our behavior to help prevent it, or if need be, help reverse its course after the fact. Fortunately, the positive effects of doing so also help us to prevail over most other threats to our wellness, and they involve eating right, exercising, avoiding exposure to toxins, reducing stress, and getting adequate sleep.

Eat Right

Cancer experts estimate that up to 90% of cancers of the prostate have a dietary link. Between various clinical trials and studies of diets among diverse populations, a number of food substances have been shown to inhibit PC cell growth and others to promote it. Men in Japan and China, for example, have up to 90 percent fewer incidences of prostate cancer than American men. That is until they migrate here and assume our lifestyle. The best evidence points squarely to a difference in nutrition as a major factor.

To maximize protection, get your carbohydrates by consuming a variety of fresh fruits and vegetables. Broaden your selections. Go for a mix of colors to get a wide range of different nutrients. Experiment with new choices and preparations till you find what appeals. Supplement your carbohydrate intake with whole grain cereals, breads, pastas and rice rather than refined products. Stick to the monounsaturated fats like olive and canola oil, and avoid the saturated fats and the partially hydrogenated oils and trans fats found in margarines, deep fat fried foods, many commercially prepared foods, poultry skin, red meat and the like. Avoid animal fat. Polyunsaturated fats have positive health benefits as well, but we usually get enough of those in commercially prepared and restaurant foods. Fulfill your body's need for protein through lentils, beans, fish, poultry white meat, small amounts of lean red meat if the urge persists, egg white/substitute, cheeses that are fat free, skim or reduced fat, and soy products -- soy milk, tofu,

tempeh and soy protein powder. Soy products have the advantage of containing genistein, shown to aid in fighting PC. Then wash it all down with a glass of red wine a day. Add an 81 mg aspirin a day on top of that. And drink some green tea. But watch your weight. There is a direct link between obesity and PC. And there are increasing indications that high levels of cholesterol (a building block of testosterone) may be associated with PC risk.

There are some other food substances shown to fight PC cell growth. Lycopene, found in cooked tomato products, tomato concentrates, watermelon, apricots, guavas and pink grapefruit, has recently been shown to have little effect on preventing localized, early stage PC. But once the cancer has formed, high levels of lycopene (or of carotenoids in general, including lycopene) may reduce significantly the risk of the tumor progressing to an advanced stage PC. And that tumor may have started developing well before you are diagnosed. Pomegranate juice, a strong antioxidant, has shown promise in lab tests. But like grapefruit juice, it may interfere with the body's metabolizing of certain prescription drugs. Lupeol, an antioxidant found in fruits including strawberries, mangoes and figs, may kill existing cancer cells and prevent new tumors from initiating or progressing. Broccoli, a cruciferous vegetable, has been shown to reduce PC risk, including the more aggressive forms. Garlic, onions and leeks have more than 30 different enemies of carcinogens. Turmeric or curcumin, the spice found in curry powder, holds real potential for the prevention and therapy of PC, especially when combined with PEITC (phenethylisothiocyanate), a naturally occurring substance particularly abundant in watercress, cabbage, winter cress, broccoli, Brussels sprouts, kale, cauliflower, kohlrabi and turnips. IP-6 (inositol hexaphosphate), found in foods like beans, brown rice, whole-kernel corn, sesame seeds, wheat bran, cornbread, grape juice and raisins, inhibits the activity of free radicals in the body, which slows the type of abnormal cell division associated with tumor and cancer growth. It's also a big help for those undergoing chemo and radiation therapy. Cranberries and their juice have a number of tumor blocking compounds. Whey protein in powder form or in yogurt is another PC fighting nutrient. Even mushrooms have significant amounts of cancer fighting antioxidants.

Vitamin B6, high in foods such as potatoes, bananas, chicken breast and prune juice, has been shown in a recent study to have strong protective effect in men with early stage PC, significantly improving their survivability.

Omega-3 deserves a special mention. Omega-3 and 6 essential fatty acids, which your body can't produce, play key roles in the functioning of your hormonal systems, and should be in balance with each other. And they were, in our ancestors' diets prior to the Agricultural Revolution. Today we get way too much omega-6 in our diets particularly from commercial foods prepared with oils from corn, soy, sunflower and safflower, all excessively high in omega-6. You can increase your omega-3 consumption by eating fatty fish from the coldest deep seas --mackerel, anchovies, herring, salmon and sardines. Be leery of farm raised salmon as a source. Their feed is often high in omega-6 and PCBs, with food coloring later added. Enquire about the source. You may still need to supplement cold water fish with omega-3 fish oil capsules on the order of 2-3 grams per day. Flax seeds are a good source, ground and kept refrigerated. Add them to salads, hot cereal or other foods or suspend them in thick juices such as tomato or V-8. The lignans found in ground flax seeds inhibit PC cell growth and actually reverse it after the fact. But avoid flax seed oil in extract form. It might actually promote PC cell growth. Walnuts are another good source of omega-3 and selenium.

Try to get all of your vitamin and mineral needs directly from whole fresh plant based foods, or in the case of vitamin D, from moderate exposure to sunlight to allow your body to manufacture and store it. Where necessary, round out those needs with supplements. Between the two you should be getting on the order of 200 mg of vitamin C, 1,000 IU of vitamin D or 2,000 IU or more if you are at high risk foror have been diagnosed with PC if you don't get much sun exposure, look for D3 choleciferol vs. D2 ergocalciferol), 400 IU of natural vitamin E with mixed tocopherols (fat soluble, take with meals), 25,000 IU of mixed carotenes, and 200 mcg (don't exceed 400 mcg) of

organic yeast bound selenium (take with the E). One caution though, if you are undergoing chemotherapy or radiotherapy treatment, antioxidants such as vitamins C and E may reduce their effectiveness.

There is a high correlation between vitamin D deficiency and incidences of PC. Some 40% of men are technically deficient in vitamin D. If you are at increased risk for PC or get very little exposure to sunlight, consider having your blood level checked for 1,25-dihydroxyvitamin D. It should be on the order of 30-50 ng/ml.

You need calcium for strong bones and a long-term hedge against osteoporosis. The RDA is 1,200 mg total. If you are at high risk for PC, don't exceed that. If you have PC, consider cutting back. If you are on hormone therapy, which tends to accelerate bone loss, consult with your oncologist for the hard choices. You also need iron. Women need even more. You normally get enough in your diet. Too much creates too many free radicals. So do not take an iron supplement. The RDA for zinc is 15 mg/day. You normally get enough without taking a supplement. Too much increases PC risk. High doses (>100 mg) more than doubles the risk for advanced PC. Taking glucosamine to relieve osteoarthritis symptoms is okay, but avoid chondroitin sulfate which may encourage cancer cell growth. Excessive selenium may increase one's risk for type 2 diabetes.

With supplements, more is not better. Some have clear toxic levels not to be exceeded. Others are more obscure. Recent findings show that more than one multivitamin a day may promote advanced PC, suggesting that some oxidation is important and too many antioxidants can be destructive. Also bear in mind that it is difficult to know just how much of a given vitamin or mineral we are actually getting without measuring our food, which few of us do. To complicate matters, many prepared foods are fortified with vitamins and minerals. Be aware and don't overdo supplements.

Keep in mind that while supplements in pure extract form may be helpful in rounding out an incomplete diet, they are generally not as effective as their source found in the original foods where their effects are enhanced by acting in conjunction with other nutrients contained in the fresh food. Go fresh where you can. And remember that supplements are unregulated with regard to purity and strength. So buy reputable brands from responsible sources.

Avoid Toxins

On the flip side of dietary intake is the avoidance of toxins that put unwanted additional stress on your immune system and in some cases promote and support tumor growth. Avoid all manner of tobacco smoke. Check your drinking water against EPA standards and filter it as necessary. Thoroughly wash or peel your fruits and veggies, and remove pesticide laden outer leaves. Or better still, buy organic, especially in place of those products normally known to be high in pesticide content – apples, bell peppers, celery, cherries, imported grapes, nectarines, peaches, pears, potatoes, red raspberries, spinach, and strawberries. Organic, naturally raised, pasture fed meat, poultry and dairy products, free of antibiotics and growth hormones and containing omega-3 fatty acids are also available at your local health food stores and farmers' markets. They may cost more, but so does cancer, and what price do you put on your good health? Avoid food preservatives and artificial colorings found in many off-the-shelf food products. In fact, many commercially processed foods contain a variety of unhealthy ingredients and should generally be avoided in favor of naturally raised/grown foods prepared at home. Don't char your meat on the barbecue. Don't over-heat cooking oils to the point of smoking and breaking down into the bad fats. Wild-caught fatty freshwater fish such as carp, catfish, bass, and trout are prime candidates for contamination. Removing skin and bones from all fish should eliminate about half of most contaminants. To avoid ingestion of low levels of bisphenol A which can cause biochemical changes in prostate tumor cells that make treatment for prostate cancer less effective, don't microwave food in plastic containers or even "micro-wave able" plastic ovenware.

Exercise Regularly

A good daily exercise regimen is essential to maintaining your immune system and fine-tuning your myriad of complex bodily functions. It should include both aerobic, anaerobic, strength, and stretching/deep-breathing components. If you don't have the habit, now's the time to acquire it. Regular exercise is one of the most important things you can do for your health, and requires a daily investment. And specifically, there is a positive relationship between exercise and wellness from cancer.

A caveat: the following are suggested optimal routines. Do what you can without torturing yourself. Whatever you can do will be beneficial - the more, the better.

(1) Make exercising a priority. Put it in your daily schedule. Don't make excuses such as "I'm too tired." or "I don't have time today." Ben Franklin had time for daily exercise; we do too. It helps if you have a variety of routines, so you don't get bored. Music helps. A good club with lots of good-looking women also helps.

(2) Warm up before exercising and stretch afterward. Stretching cold muscles is not the best way to do it.

(3) Lift weights. This is as important as cardiovascular exercise, and is actually easier. Use machines or free weights. Exercise all major muscle groups, each with one set of 8 -12 repetitions, with each repetition taking six seconds. If you can lift 13 or more times in a set, you need to add weight in your next session. In short, the last repetition should be to failure. See anaerobic exercise below, and notice that this is basically a one minute anaerobic interval - 10 reps x 6 seconds. Lifting weights to failure sends all sorts of good messages to your muscles: "This guy will kill us if we don't get strong." Lift 2-3 days per week. Don't punish the same muscles two days in a row. They need rest.

(4) Do aerobic exercise every day, 20 minutes on weight lifting days and 30-60 minutes on other days. Take your pulse. Aerobic means your muscles are burning oxygen, heart rate about 110-120 bpm at our age. Getting your pulse up to aerobic level should be easy. Running, biking, swimming, dancing, or machines such as treadmills, steppers, elypticals, rowers and cycles are all good. To combat boredom when indoors, use music or TV. Do not, however, just grind away at a steady sub-aerobic or aerobic pace for an hour or so. That's actually bad - unless you mix in anaerobics! See Wikipedia for a good discussion of anaerobic exercise. What's needed are intervals of anaerobic bursts of one minute each at 95% effort or 140-160 bpm depending on your condition. A good workout: 10 minute warm-up, then 5 minutes aerobic, then 1 minute anaerobic, then 4 minutes easy recovery, then another 1 minute anaerobic, and repeat for the duration of your workout. This does not have to be torture. It's actually easier than just grinding away - and much better for you.

(5) Play sports that make you go anaerobic. Even at age 70+ we can still play sports, if our joints are OK. Tennis, basketball, volleyball, badminton, squash and racquetball are good examples.

(6) Spend a few minutes after exercising to stretch and do deep relaxing breathing.

(7) Consider adding an activity like yoga, tai chi or Pilates, which incorporates stretching, strengthening, and balance. If all this seems impossible, remember that lots of people do it, and enjoy it. Working out with friends helps.

If you want to look good, feel good, and stay in good health, regular exercise is the ticket. Get the habit. "Just Do It!" If that seems difficult, just talk to anyone who has been afflicted with PC. The

experience will make you determined to do everything you can to avoid contracting it. And if you do get PC, you'll be better equipped to survive if you're in good shape and stay that way.

If you have been ill or have otherwise gone a long time without regular exercise, consider first getting a complete physical exam, including a stress ECG. And if your doctor (preferably a jock himself!) gives the green light, then force yourself to get back into it. Take it slowly, one step at time. But keep at it. Doing what is comfortable is better than doing nothing.

There are many folks today in their 80's and 90's who work out every day. More and more research shows that there is nothing as good for you as physical activity.

Sleep Well

Sleep is critical for maintaining an effective immune system. It's our body's natural mechanism for restoring its homeostatic balance and recovering from the impact of daily life on our physical and mental systems and feelings of well being. Aging takes an added toll on our ability to get adequate, restorative sleep. BPH gets us up to urinate several times a night (nocturia). We don't produce brain chemicals in the same amounts, and the brain doesn't respond to these chemicals as effectively. We have more on our minds, we get stressed out by more complex issues, and we're more apt to be depressed.

Here are some helpful suggestions: If you have trouble falling asleep after about 30 minutes, get out of bed and do something else until you feel tired. Go to sleep and get up about the same time every day, varying not more than an hour on weekends. Put at least two hours between dinner and going to bed, especially if you are prone to heartburn or indigestion. If you have nocturia, stop drinking liquids early in the evening. Avoid caffeinated drinks and alcohol three hours before bed time. Be cautious about using sleeping pills; older people are at higher risk of side effects. For example, for those with BPH, the use of diphenhydramine, an antihistamine (found in brand names like Nytol, Sominex, Sleepinal, Compoz) as a sleep aid can make it difficult to urinate. However, if BPH is not an issue, Benadryl, an antihistamine, is well tolerated, not habit-forming, has no after effects, and may aid in getting to sleep for most people. Being tired from a good workout may be helpful, but avoid busy or stressful activities late in the evening; rather unwind and relax. Get a short afternoon nap in, but not beyond 3 p.m. If you have a sleep disorder such as sleep apnea, get it treated. If there are physical or emotional issues interfering with your developing and maintaining consistent, effective sleep patterns, learn how to overcome them, get them resolved, and seek professional help if need be.

Melatonin, the hormone which regulates the circadian rhythm to determine when we fall asleep, is often found to be at reduced levels in those with PC and heart disease. It has also been shown to block PC cell growth in lab studies. If your melatonin level is low for whatever reason, if you have frequent jet lag or poor vision, or if you typically operate on a reverse cycle, consider melatonin supplementation. Dosage levels have not been established, and too much may cause anxiety and irritability. So start with a very low dose, follow timing guidance, and check for interactions with other drugs. Or alternatively, meditation may cause melatonin levels to rise and can be a valuable addition to the treatment of PC.

Avoid Chronic Stress

Stress is good—up to a point. It keys our bodies to perform at higher levels of efficiency, be it the fundamental fight or flight response to danger or responding to sudden pressures imposed by the work place or modern day environmental factors, and it prepares us to meet a tough situation with focus, strength, stamina, and heightened alertness. Adrenaline and cortisol are released into the bloodstream to speed up heart rate, breathing rate, blood pressure, and metabolism. Blood vessels open wider to let more blood flow to large muscle groups, putting our muscles on alert. Pupils dilate to improve vision. The liver releases some of its stored glucose to increase the

body's energy. And sweat is produced to cool the body. All of these physical changes prepare us to react physically in a quick and effective manner to handle the pressure of the moment.

In today's environment, however, our stressors and responses thereto tend to be more emotional than physical. And ongoing emotional stress and response can produce chronic stress symptoms, which is bad. The continued low level release of hormones over time without accompanying physical exertion adversely affects our immune system and tends to elevate our PSA levels. Yes, there is a direct correlation between PSA and stress levels.

If chronic stress is a major part of your life, make a concerted effort to eliminate or attenuate the stressors. Change your lifestyle where appropriate. Seek control, information, predictability and solutions. Where these are elusive, find outlets for relieving stress -- exercise, prayer, meditation, yoga, psychotherapy, guided imagery, sports, music, and the like. Exercise has the fastest and most dramatic effect on reducing stress. Find sources of social affiliation and support. As the Cadet Prayer encouraged us, "Grant us new ties of friendship... Kindle our hearts in fellowship with those of a cheerful countenance..." And the AA prayer pretty well sums it up -- "God, grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference."

If need be, get professional help through the many hospitals, medical schools and freestanding clinics offering programs that help you learn various techniques for stress management. One of these is therapeutic biofeedback to help develop the ability to monitor and control certain physiological processes through structured stress and anxiety reducing interventions. There are interactive computer software programs that apply biofeedback techniques available for home computer use.

Know Where You Stand

By all means, get PSA and DRE tests once a year. Don't be content with being told that "Your PSAT score is normal." Get your current and previous three year numbers and look for change or "velocity". At our age an annual increase of 0.6 ng/ml or more (0.4 for the <60s) is a definite red flag, even if you are within the so called normal range -- <4.0, or <3.0 with a family history of PC. But don't panic. An elevated PSAT score could be caused by a benign infection that a few weeks of antibiotics may remedy. Or it could be elevated by having had an orgasm within 48 hours prior to the test or by a recent trauma to the prostate such as a catheter insertion. Or your provider may have switched labs having differently calibrated instruments. Be aware that to start taking statins to control cholesterol, or saw palmetto or various drugs to control BPH may produce a change from your previous baseline and affect interpretation of your numbers. Consult with your urologist on that. Beyond the daily 81 mg. of aspirin, taking a dose of aspirin or other NSAID before a PSAT can reduce the score and affect interpretation. Seasonal variations too can affect the score by as much as a 0.5 ng/ml rise in the summer.

If it is determined that a biopsy is in order, then go for it. Be guided by one of Gen. Creighton W. Abrams' memorable aphorisms: "I have never known bad news to improve with age." If PC is caught in its early stages, your treatment options and likelihood of an effective cure are greatly enhanced.

Some 10% of white males (20% of black males) have elevated PSA levels due to elevated levels of parathyroid hormone that regulates calcium in the blood and can produce prostate cell growth without prostate cancer. If your PSA is consistently high, that may be the reason, in which case a biopsy is not indicated. Remember, it's the change in PSA level, the velocity that counts.

For those who have consistently elevated PSA levels and have had one or more standard transrectal prostate biopsies (TRPB) with negative results, if yet another biopsy is called for, ask for the newer stereotactic transperineal prostate biopsy (STPB) which has shown in a recent

study to have a greatly enhanced level of confidence in detecting the presence or absence of cancer, and more specifically, the exact location of the cancer within the prostate.

Risk Factors

Risk is a major consideration in testing for PC and choosing to take preventive measures, and there is a strong genetic component involved. If you have one or more family members who have been diagnosed with PC or ovarian or breast cancer, you probably have a greater risk of contracting PC as well. Being genetically predisposed does not mean you will get PC yourself. But it does mean the triggers are more sensitive and you need to take greater precautions in lifestyle choices and being tested for PC.

Being overweight is not a threat. However, obesity (a Body Mass Index of 30 or more) not only increases PC risk, but it tends to distort PSAT score readings downward (lower PSA concentrations per volume of blood) and increase the possibility of advanced cancer. Again, look for year to year change.

Mind-Body Connection

If you have been diagnosed with PC, the above guidance becomes doubly important to follow. But you also have yet another tool in your arsenal to apply to enhancing your immune system's performance--your mind. We're not sure how it works, but there is a definite link between your immune system and your mind. It's called the mind-body connection, and we are all familiar with one of its subsets, the "placebo effect." We often hear the terms "miraculous cures" and "spontaneous remissions." They are neither miraculous nor spontaneous. Rather they are most often the result of a sick individual making major life style changes and becoming convinced in his mind that they will enable him to prevail. Those changes could be in the form of diet, exercise, the developing of supportive social relationships, the application of religious faith, the use of visualization techniques, or implicit faith in one's doctors and treatments, or a combination thereof. The net result is the mind triggering that mind-body connection, however it works, to boost the immune system. It may not always bring about a cure, but it will certainly help the process. And for the mind to best do its job, we need to keep it sharp as we age. That means exercising it with such activities as crossword puzzles, sudoku, learning a foreign language or musical instrument, problem solving, memorizing a poem or passage and the like--anything that challenges your intellect. Reducing stress, expanding social relationships, proper diet to include antioxidants and omega-3, exercise, and the judicious use of alcohol (1-2 drinks max per day) have also shown to help keep the mind sharp as we age.

Making Changes

For most of us, acting on the advice given here requires a significant degree of behavioral modification. Change can be scary. It entails giving up that which is known and comforting to us for the unfamiliar and therefore seemingly difficult and/or unpleasant. Doing so effectively can only come from doing your homework, understanding the facts, assessing the risks and rewards normally associated with alternative behaviors and deciding that change is in one's overall best interest. What is the current likelihood of your contracting PC? What are the probable consequences if you do? What changes are you willing to make in order to avoid these? The problem is we don't really know the answer to that first question until it's too late, in which case this guide becomes doubly important to follow to enhance your chances of survival, when the question then becomes what changes are you willing to make to survive? Bear in mind that a diagnosis of PC is a wake-up call, a stark reminder that your ongoing lifestyle up to that point did not afford you the protection necessary to avoid contracting the cancer, given whatever circumstances may have led to the diagnosis. It's high time for some major changes.

An excellent companion to this guide is Dr. Dean Ornish's book "The Spectrum" which provides the "why" and the "how' to the guide's "what". To paraphrase Ornish, don't think of change in terms of deprivation and sacrifice, but rather what we gain is so much more than what we give up. Be motivated by the joy of living, not the fear of dying. And remember, it doesn't have to be all or nothing. Every little bit helps.

And finally...

We hope this guide will help to point you in the right direction for achieving and maintaining wellness and avoiding PC or stopping it in its tracks once diagnosed. Volumes have been written and exhaustive studies have been conducted on the many subjects we have touched upon. There are still many unknowns surrounding the causes, prevention and treatment of PC, and this guide is a consensus of what we as informed laymen consider to be the best information available at this time. As new and better information becomes available, we will do our best to disseminate it, and if you acquire information that you believe is relevant, please let us know. If you would like references for further understanding of the subjects discussed here, or if you have suggestions for improving the utility of this document, contact the PC list moderator for assistance. The best thing you can do for yourself, your family and friends is to get informed and get involved.

Additional Reading:

Carroll, Peter R., et al., <u>Report to the Nation on Prostate Cancer: A Guide for</u> <u>Men and Their Families.</u> 2005. Prostate Cancer Foundation.

Marks, Sheldon, MD: <u>Prostate & Cancer. A Family Guide to Diagnosis</u>, <u>Treatment & Survival.</u> 1999. Fisher Books.

Walsh, Patrick C., MD, and Janet Farrar Worthington: <u>Dr. Patrick</u> <u>Walsh's Guide to Surviving Prostate Cancer.</u> 2001. Warner Books (Dr. Walsh of Johns Hopkins pioneered the nerve sparing surgical techniques now in general use).

Moyad, Mark A. M.P.H., <u>The ABC's of Nutrition & Supplements for</u> <u>Prostate Cancer.</u> 2000. Sleeping Bear Press.

Ornish, Dean, <u>The Spectrum</u>, 2007, Random House.

Links (for starters):

www.prostate.com

www.prostatecancerfoundation.org

<u>www.cpdr.org</u> (Department of Defense Center for Prostate Disease Research)

<u>www.auafoundation.org</u> (American Foundation for Urologic Disease)

www.ustoo.com (US TOO! International)

www.cancer.org (National Cancer Institute)

<u>www.aicr.org</u> (American Institute for Cancer Research; offers educational info and current research on the relationship between diet and cancer)

www.americanheart.org (American Heart Association)

www.eatright.org (American Dietetic Association)

www.johnshopkinshealthalerts.com/bookstore/prostate.html

CLASS OF 1960 PROSTATE CANCER SUPPORT GROUP GUIDELINES FOR PARTICIPATION

First of all, if you, as a member of the Class of 1960, want to join the support group, send an e-mail message to the list moderator (currently Dick Healy: <u>dhealy60@comcast.net</u>) or the alternate (currently Bill Hanne: <u>mbmeh@earthlink.net</u>). One or the other will get you on the list and help you get started. The lists are closed for the simple purpose of confidentiality. Participation requires adopting the guidelines (below). Although the support group was initially aimed only at Prostate Cancer (PC), we expanded coverage to include other maladies suggested by classmates. Therefore, there will be two lists, one for prostate cancer and the second for the other medical problems (currently colon cancer, kidney disorders, macular degeneration, melanomas, Parkinson's Disease) flagged for attention. You will find the names of classmates, who choose to do so, on the lists who are afflicted with a specific disorder or who have special information about the disorder or treatment for it. They are available for direct contact.

A. FOR ALL LIST MEMBERS:

1. Our group's objectives are to:

a. Provide moral support to those classmates who have been afflicted with PC or other illnesses.

b. Enable those previously afflicted to assist and support each other during and beyond initial treatments.

c. Enable newly afflicted members to seek advice and assistance from those previously afflicted, keeping in mind that individual circumstances and priorities for treatment vary, so one's choices may not be best for another.

d. Assist members in finding information about prevention, treatment options and post treatment lifestyle modification options.

e. Assist members in finding information about various issues relating to benign prostatic hyperplasia/hyper- trophy (BPH) and other pre-cancerous prostate problems.

2. Keep in mind that individuals have differing motives for participating in the PC support group. Be understanding and supportive of each other's differences. Treat all parties with respect, apply rational thought to one's input, and take responsibility for what one posts on the system.

3. The real success of this group will be best achieved by establishing and maintaining an environment in which we all feel comfortable speaking openly and discussing sensitive issues that are personal in nature. Lend your personal support to that goal by:

a. Treating all discussions confidentially and not discussing content of a personal nature outside the group without the express permission of the individual concerned.

b. Being sensitive to the feelings of others when approaching individuals to request personal information and in framing your message responses to the group and to individuals.

4. Vital to overcoming threats of PC and other prostate afflictions is the timely sharing of relevant information with the group. Whenever and wherever you encounter such, make the effort to get it on out to us. When in doubt, err on the side of getting it on out there.

B. FOR THOSE WHO HAVE (OR HAD) PROSTATE CANCER

1. Identify yourself to the list moderator with the year diagnosed (XX), the type of treatment (Y) selected [e.g., surgery (S), radiation (R), hormones (H), watchful waiting (W) or multiple options (M)] and let him know whether or not you choose to be identified on the list with a (PC-XX-Y) by your name indicating that you are available to consult with other list members on a one-on-one basis to discuss treatment options, post treatment issues and/or receive/provide moral support.

2. If you wish, complete the attached Prostate Cancer History form for your own use in giving information easily and simply to those you wish to have it.

3. Answer inquiries from others if you wish, or do not. Your choice.

4. If you wish, send the list moderator your completed history form for inclusion in a master worksheet, to be held in confidence, showing the same information for each volunteer respondent. The information provided may be used for statistical analysis to develop trends of interest to all list members presented in an anonymous format.

5. At some point you may wish to share your history anonymously in narrative form with the group. This would allow you to preserve confidentiality while helping others by enhancing their awareness of the resource base available to them and providing them with a means of contacting you directly if you are so willing. The list moderator will assign an ID number to the document and post it to the list. Anyone wishing to consult with you on your history would first need to

contact the list moderator or his alternate for approval. Do not include information that you would not want to discuss with someone directly. You may also post an anonymous history and elect not to be contacted. Your choice.

6. When you consult with others, avoid recommending any specific course of treatment. Remember that goals and treatment options vary for each individual and that treatments will be changing and improving over time. This is a matter for each patient to determine with his physician.

7. The best advice you can give a newly afflicted classmate is to recommend that he follow the suggestions below.

C. FOR THOSE WHO HAVE JUST BEEN DIAGNOSED POSITIVE FOR PROSTATE CANCER:

1. Get a second opinion. For those who retired from the military, the Center for Prostate Disease Research (202-782-4000) at Walter Reed AMC is available as a resource (consultation and treatment).

2. If you did not already get a biopsy, get one, from a doc/hospital with lots of experience. Experience counts. Biopsies used to be associated with pain, but that is no longer the case. It isn't real comfortable, but it simply doesn't hurt and should not be avoided for that reason. Learn about the Gleason Score. Learn your Gleason Score for each positive sample, and the location of each. Get a drawing of it.

3. If your urologist doesn't explain all the current treatments (See the Internet.), and all the pros and cons, get a new urologist.

4. Determine your goals, and be honest with yourself. Here are some things to consider:

a. What is really most important to you – your quality of life in the short term, or your best chance for long-term remission?

b. What are your priorities? Best chance for getting rid of the cancer? (There is no sure cure, but the odds are greater or lesser depending on the stage of your cancer and whether it has escaped the prostate.) Best chance for bladder control? Best chance for an active sex life? Rank these 1, 2, 3.

c. Discuss your goals with your significant other. She may have different goals, and hers may change yours!

d. Discuss your diagnosis with as many physicians (not urologists or surgeons) as you can, asking them this question (do not prompt them): If you had my diagnosis, (1) what treatment would you have, (2) who would do it, (3) where would you go to have it done, and (4) why to those questions.

e. Contact the list moderator or his designated alternate. He will provide you access to a list of previously afflicted list members and the treatments they

selected so that you can consult with them on a one-on-one basis. Their experiences may help you in your treatment selections, keeping in mind that their priorities and available treatments may differ from yours. Also let the moderator know how much information about your situation you want released to other list members.

- f. Decide on a course of treatment.
- g. Get it done as soon as possible.
- h. Follow instructions for recovery/rehab, etc.

i. Follow a healthy lifestyle – no cigarettes, low saturated fat intake, low refined sugar intake, take an aspirin per day, get lots of exercise, and plenty of rest. Lower stress levels. Consult your physician on dietary supplements that will agree with your system. Make sure you consume plenty of lycopenes, soy, omega-3 fish oil, IP-6's and whole grains from their natural food sources. Help your immune system to help you.

j. Remember that none of us will get out of this life alive, anyway.

k. If you're on speaking terms with God, have regular conversations. If you aren't on speaking terms, negotiate some terms.

I. Finally, do the things that we all put off, but which should be done and updated on a regular basis. This goes for everyone, cancer or no cancer:

- (a) Do a checklist of where your things are.
- (b) Do a good financial statement.
- (c) Do a good will with specific bequests and final instructions.
- (d) Let your loved ones know you love them.
- (e) Make good notes for whomever does your Assembly memorial.
- 5. Do all these things, and you'll be able to enjoy life without worrying about it.

D. FOR THOSE WHO HAVE NOT BEEN DIAGNOSED POSITIVE FOR PROSTATE CANCER:

1. 1. Get your PSA (prostate specific antigen level) checked at least once per year, or more often if you have problems such as trouble urinating or frequent urination. The PSA is a simple blood test that requires no fasting. If your PSA is elevated, your physician may recommend further testing. Try to get a test that will give your Free/Bound PSA percentages. The PSA test should be done in combination with a DRE (digital rectal exam), that searches for anomalies on the back side of the prostate.

2. You might consider keeping track of your annual PSA readings with a simple list just as a reference. Such a listing will help you quickly see spikes should they

ever occur. Jumps in readings (velocity) from whatever base should be of concern to you and your doctor.

3. Maintain good general health, which means regular exercise and a diet that includes lycopenes, garlic, soy, IP-6, omega 3 fish oil, fresh fruits and vegetables, and whole grains. Use dietary supplements where needed. Take an aspirin a day. The regimen for the prostate is nearly identical to that for a healthy heart.

4. Avoid excessive saturated fat. This seems to be associated with cancers of the colon and prostate.

5. Stay informed, and have a general idea of what to do if you develop PC. Help other list members stay informed by passing on pertinent information that you come across.

E. FOR THE LIST MODERATOR:

1. Maintain list currency through submissions to WP-ORG and provide list members with updated changes to the list at least monthly.

2. Promote open, free discussion among list members while insuring the maintenance of appropriate levels of confidentiality and sensitivity to others.

3. Insure that the class at large maintains awareness of the services provided by and to the list membership by periodically providing information to the class on list objectives and status, and encouraging classmates newly diagnosed with PC to join the list.

4. Make early contact with any classmate newly diagnosed with PC, invite him to join the list if he has not already done so, and explain how he might be supported by the list membership. Should he choose to join or is already on the list, sort out with him the level of exposure with which he is most comfortable –

- a. moderator does not tell anyone on the list about the diagnosis, but provides him with a list of (PC) members and their treatments so that he may contact whomever he wishes to seek guidance on selecting treatment options,<u>or</u>
- b. moderator notifies only the (PC) members so they can contact him to offer help, <u>or</u>
- c. moderator informs the entire list so the classmate can receive fairly broad support. Where he wants to be contacted by (PC) members or the list members at large, moderator will make that clear to the appropriate group and provide his phone number and email address. Moderator will encourage list members to initiate contact with him by phone or email depending upon their level of compassion and/or desire to help. Moderator will check back with him within a week to see if he is comfortable with how we handled it and find out what else we can do.

Should he choose to not join the list, moderator will, with his permission, notify the (PC) members of the situation and ask them to contact him. Similarly, moderator will follow up in a week.

5. Insure an alternate moderator is designated, known to the list as such, and kept informed of all appropriate ongoing list activities.

6. Maintain a confidential database of PC information received from list members.

7. Maintain a confidential database of submitted anonymous histories published to the list, assigning each an ID number. Direct individuals wishing to consult with the authors to them based on the latter's personal preferences.

8. Maintain a Treatment Selection List of (PC) members showing the dates of their initial PC diagnosis and the treatments selected by them. Provide a copy of the list to newly diagnosed members and informing them to handle the treatment information in a confidential manner and use if only for contacting selected (PC) members for support and treatment advice.

9. Coordinate with the list member designated to maintain the PC web page on use and content of the page.

10. Interface with outside entities such as other class PC list moderators and representatives of PC study organizations to coordinate activities of interest to the list members.