PROSTATE CANCER – NOT TO BE TAKEN LIGHTLY!

Observations of Wichita Chapter Us TOO
Members through research, reading p2p (physician to patient) exchanges, or having attended or reviewed recordings of presentations at annual National Conferences on Prostate Cancer by nationally recognized physicians who specialize in Prostate Cancer

1. The following observations are not intended to replace consultation with members of the medical profession, but rather to bring to your attention information that may provide you additional insight to be discussed with your physician.
2. If you have received treatment for prostate cancer and believe that you have been cured of this disease, WAKE UP! (Oncologist Charles "Snuffy" Myers, MD). This erroneous belief in cure could only come from you or your physicians. If it came from you, get your facts straight; if it came from your physician, it is time to get a second opinion! Experts have made great strides in diagnosis and treatment, but are still early in understanding dormancy.
3. Many physicians harbor old erroneous ideas about prostate cancer and the treatment of it, or of the treatment of the complications of the treatment of prostate cancer. It is difficult to root out erroneous beliefs.
4. Prostate cancer is an elusive disease that can begin in males past puberty and remain dormant or in remission for years, and for many for their lifetime (even AFTER treatment). Continuing questions are: What keeps it dormant or in remission? Diet? Biological factors? Genetics? Why and when will it become active or aggressive?
5. Prostate cancer is very, very common, and increasingly common with increasing age.
6. Even today when men learn they have prostate cancer, in 50% of them the disease has already metastasized to bone marrow; much better than 20 years ago when the figure was 95%.
7. There is great need for earlier diagnosis and the option to enter effective treatment before the cancer has metastasized. Don't rush into accepting the first treatment offered. Take some time learning about your cancer and get second opinions from experts.
8. If a prostate cancer patient's disease has spread to just one lymph node, there is a 95% likelihood of recurrence within the next ten years.
9. PSA doubling time is of particular importance; a doubling time of less than 2 years means that prostate cancer has become active or aggressive. Soon we may have better predictors.
10. The prostate is a target organ for hormones, mainly testosterone. Testosterone (T) enters the prostatic epithelial cells where it interacts with androgen receptors to stimulate DNA production and the eventual secretion of multiple proteins. PSA is one example. Most importantly, T (testosterone) is converted by the 5-alpha reductase (5-AR) enzyme to a FIVE TIMES MORE POTENT Dihydro-testosterone (DHT) which has more avidity for the androgen receptor than does testosterone. Blocking DHT to reduce intra-cellular levels is therefore an important part of androgen deprivation therapy (ADT). ADT is highly effective at slowing most Prostate Cancer.
11. Therapy to block the conversion of testosterone to DHT includes the 5-AR reductase inhibitor finasteride, which is manufactured under the trade name Proscar.

Finasteride inhibits a Type 2 enzyme in prostate cancer cells and has been found to reduce prostate cancer incidence in 25% of the men to which it has been prescribed. A newer drug, dutasteride, manufactured under the trade name Avodart, may work even better since it inhibits both Type 1 and Type 2 enzymes in the prostate cancer cell that otherwise convert T to DHT.

12. An excerpt from the Physician's Desk Reference (PDR) regarding Avodart (dutasteride) (and likely would apply to Proscar/finasteride) is important to those men prescribed Avodart either as a medication for Benign ProstaticHyperplasia (BPH) or when taken as a maintenance drug during an intermittent off-phase from androgen deprivation therapy (IAD):
"Effects on PSA and Prostate Cancer Detection: Digital rectal examinations, as well as other evaluations for prostate cancer, should be performed on patients with BPH prior to initiating therapy with Avodart and periodically thereafter. Dutasteride reduces total serum PSA concentration by approximately 40% following 3 months of treatment. This decrease is predictable over the entire range of PSA values, although it may vary in individual patients. Therefore, for interpretation of serial PSAs in a man taking Avodart, a new baseline PSA concentration should be established after 3 to 6 months of treatment, and this new value should be used to assess potentially cancer-related changes in PSA. To interpret an isolated PSA value in a man treated with Avodart for 6 months or more, the PSA value should be doubled for comparison with normal values in untreated men.
13. In a patient with newly diagnosed prostate cancer going on ADT (Androgen Deprivation Therapy), as well as a patient returning to ADT after an intermittent interval, the ADT should be preceded by administering an anti-androgen such as flutamide (Eulexin), bicalutamide (Casodex) or nilutamide (Nilandron) for seven days along with finasteride (Proscar) or dutasteride (Avodart) to prevent both biochemical and clinical flare, which manifests as a testosterone surge and an increase in PSA. Then a 28-day formulation of either Lupron or Zoladex should be used, the PSA monitored, and a chem panel and CBC done at each 28-day visit while also assessing the testosterone to make sure it has dropped to less than 20 ng/dl.
14. Other biomarkers that should be checked at baseline and whenever the clinical course is taking a turn in the wrong direction are: PAP (Prostatic Acid Phosphatase), CEA (Carcino-Embryonic Antigen), CGA (Chromogranin A), and NSE (Neuron Specific Enolase). Other new markers like the assay of TGF-B1 and IL-6sR may be useful.
15. If on ADT, it is important to recognize that common side-effects are bone resorption and anemia.
16. Anemia can be assessed by the CBC – more specifically by the red blood cell count (RBC) and Hemoglobin (HGB). It is only a matter of time for anemia to develop and it can be treated with Procrit.
17. Two terms to understand if you are on ADT or are contemplating ADT:
<u>OSTEOBLASTS</u> – which promote BONE REGENERATION – and –
<u>OSTEOCLASTS</u> – which TEAR DOWN BONE.

    ADT takes away androgens that promote osteoblasts which regenerate bone and takes away a major inhibitor of the osteoclast, which tears down bone. The result can be Osteopenia or Osteoporosis. Yet, ADT is often the best line of defense to control

prostate cancer. Over 90% of men NEWLY DIAGNOSED with prostate cancer have been found to have Osteoporosis (63%) or Osteopenia (32%)

18. It is important that baseline and periodic testing is done to determine bone mineral density as a measure of bone resorption. According to Stephen B. Strum, M.D, the appropriate test is only by QCT BMD (Quantitive Computerized Tomography Bone Mineral Density); the more commonly used technique to evaluate bone mineral density, the DEXA scan, is too often falsely "improved" by arthritis and calcium deposits in blood vessels close to the bones being studied. Both the DEXA scan and QCT BMD scan are approved by Medicare but it is important that the facility providing the scan ensures that their submission for payment indicates specifically that this was a "Bone Density Scan." In the event of Osteopenia or Osteoporosis, the initiation of bisphosphonate plus bone supplement plus vitamin D therapy should begin to prevent osteoclastogenesis (the activation of the cells that break down bone: the osteoclasts). (See next item)
19. Bisphosphonates Aredia (Pamidronate) or Zometa (Zoledronic Acid of Zoledronate): If, because it has been determined you have excessive bone resorption, your physician is going to administer for the first time a bisphosphonate injection of either Aredia or Zometa, it is important that the initial dosage is low to ensure against Acute Phase Response (APR). The maximum initial dosage for Aredia should be no more than 30mg and for Zometa 1mg. Once it is determined the system will tolerate either of these drugs, the dosage can be carefully increased. A comprehensive bone supplement such as Ultra Bone Up (Jarrow) or Bone Assure (Life Extension) should also be used. Note that the Pyrilinks-D (Dpd) urine test should also be followed to insure that excessive bone resorption has been halted.
20. If on ADT, those with allergies should be aware if your family physician prescribes prednisone to help the allergy. Since prednisone ALSO causes a withdrawal of androgen just as ADT does, and you would be compounding the problem and increasing the probability of bone softening, you should bring this to the attention of your family physician.
21. The pros and cons of treatment prompted Dr. Strum to remark: "All of biology is a two-edged sword. When we learn to emphasize the good over the negative effects of our therapies, we enhance patient outcome."
22. Are you on ADT? If so, is your physician testing both your PSA and your serum testosterone levels? As Dr. Strum comments: "Can you imagine assessing a hypertensive patient without a blood pressure or a diabetic patient without a blood sugar?" Serum testosterone levels MUST be shown to become castrate using most forms of ADT and to remain there with interval testing until the physician feels assured that this highly important goal has been achieved. Assessment of androgen deprivation therefore mandates that testosterone levels be obtained monthly during ADT until two consecutive "castrate" values are achieved. Castrate levels are defined as <20 ng/dl (<0.69 nM/L).
23. Some prostate cancer produces very little PSA. And a PSA value lower than 4 or higher than 1000 does not necessarily determine the severity of the disease.

24. It is important that as a patient you maintain your own, personal, medical file/history. Ask your physician for copies of every lab report, of pathology reports/explanations, and keep yourself aware of what is occurring in the treatment of your disease.
25. If there is a history of prostate cancer in the first degree relative(s), PSA testing should begin at 35 years of age. Otherwise, ALL men should begin to have PSA testing starting at the age of 40 with regular testing done every year. However, if the first 2-3 years of testing reveals a PSA value of less or equal to 1.0, this would indicate a normal, healthy prostate and testing could be stretched out to every 3-4 years.
26. Even earlier than 40 years of age men should begin maintaining a watch on their testosterone level. Have your testosterone level checked to establish a baseline. There is research that indicates low testosterone may bring prostate cancer out of remission.
27. When you are given a critical piece of biological information such as the Gleason score, it always should be VALIDATED by an expert. This means a second opinion BUT WITH SOMEONE IDENTIFIED AS HIGHLY TALENTED in the field of reading the pathology material from men with prostate cancer. And, it is important that the pathologist quantitate the percentage of cores with cancer and amount present in each grade of the Gleason score.
28. For the vast majority of men who present with levels of PSA less or equal to 10 and Gleason scores less that (4,3), the CT scan and bone scan are TOO INSENSITIVE to yield any significant amount of pathology and waste about 240 MILLION bucks each year in the USA alone. This is just adding to the costs of healthcare and accomplishing little. When prostate cancer patients are united in their efforts, their combined voices will speak to the absurdity of this routine practice of bone scans, CT pelvis and abdomen as "Definitive" staging for men newly diagnosed with prostate cancer. (Dr. Strum)
29. When a patient presents with a high Gleason score, an all out approach must be used to reduce the amount of prostate cancer. The use of ADT with two drugs is not going to be successful in a situation where Androgen Independent Prostate Cancer (AIPC) is most likely present. Therefore, not only using more aggressive ADT (ADT3 or ADT4) but also adding to that the use of drugs that have a broader spectrum such as the estrogenic compound DES (Diethylstilbestrol), enzyme inhibitor HDK (Nizarol/ketoconazole) and chemotherapy are important considerations EARLY on.
30. In commenting on nausea and hot flashes as the result of chemotherapy, Dr. Strum remarked that drugs like Zofran, Kytirl, or Anzemet can be used orally or intravenously to prevent nausea.. Hot flashes can be treated either with 400 mg Depo-Provera injection or the use of Effexor 12.5 mg twice a day or a combination.
31. In commenting on the use of Thalidomide for an advanced stage of cancer, Dr. Strum remarked that Thalidomide would not be a consideration for him given its highly constipating effect on top of its dulling of the mental status.
32. When taking Nizoral (HDK) you need to check the blood levels and relate to the issue of absorption of the drug in order to know how much Nizoral really is getting into your system. There are steps to take to increase the absorption to a level which is therapeutic. (Israel Barken, MD, Urological Oncologist Specializing in Prostate

Cancer Coaching, Medical Director Prostate Cancer Research and Education Foundation, San Diego, CA)

33. Control of pain. Discuss with your physician IV Stillbestrol and it's side effects. A daily IV treatment in your physician's office takes only a few minutes and, if effective for you, can provide long-term pain relief. (Dr. Barken)
34. For patients who failed chemo and all other treatment, slow release Somatostatin analog injections every 2-4 weeks should be considered. It is relatively non-toxic and works well. Check IGF-1 levels as a marker to follow-up. (Dr. Barken)
35. The Prostate Cancer Research and Education Foundation offers fee-for-service personal coaching to discuss the pros and cons of treatment options. The fee is a structured donation to PC-REF to enable them to continue their mission of providing seed money grants to fund new research for prostate cancer. To find out more about personal coaching, send an email to friedazipora@hotmail.com or call 619-461-8181 to schedule a coaching session. (Dr. Barken).
36. Cryoablation, or freezing, of the prostate: The PCRI Insights February 2005 edition contains an excellent article "Cryoablation of the Prostate" describing how this prostate cancer treatment option has improved, what the procedure entails, and statistics as to its viability in relation to the other options normally suggested to the newly diagnosed PC patient. To access the PCRI website, click on www.pcri.org. Then click on "Newsletters," and from there browse to the PCRI Insights February 2005 edition.
    (Note for Medicare patients: Current Medicare regulations authorize payment for cryoablation as a first treatment option for PC. As a treatment option as "salvage" therapy following a failed first treatment option, it only authorizes cryoablation as a salvage treatment following failed radiation treatment, and even then the patient must meet certain parameters. It DOES NOT authorize cryoablation as a salvage treatment following a failed first cryoablation treatment.)
37. Treatment and knowledge of prostate cancer is changing rapidly so some of the observations and facts contained herein may become outdated or proved incorrect. Please keep in touch with your physician and other reliable sources of information on prostate cancer treatment. You owe it to yourself and your family to seek valuable, accurate information so as to avoid ill effects for the rest of your life. If you have access to the Internet there are many websites with information regarding the treatment of prostate cancer. For those of you who do not have a computer, the Via-Christi Cancer Resource Center has them available for your use and will help you access the internet. A few websites with excellent information regarding prostate cancer are noted and you will find links on these sites to yet additional websites.

    www.ustoowichita.org Wichita (Kansas) Chapter – Us TOO
    www.ustoo.org Us TOO National Headquarters
    www.pcri.org Prostate Cancer Research Institute
    www.pcref.org Prostate Cancer Research and Education Foundation
    www.bostwicklaboratories.com Bostwick Laboratories is a pathology reference laboratory.