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♦ PROSTATE CANCER SURVIVOR: A PHYSICIAN'S TALE ♦

by
C. M. Papa, M.D.

There are several "in jokes" that doctors like to repeat to their colleagues; the first is that "Doctors make the worst patients;" the second is "That if anything can possibly go wrong, it will happen to a doctor or his family." With those grim assessments in mind, read my personal story and decide for yourself.

First, let me advise you that I am not a urological specialist. I served as the head of a division of dermatology in an academic setting at a medical school and its teaching hospital. I never gave much thought to my own urological system until 1989, when, at age 57, prostatitis showed up along with an enlarged prostate. Two years later the condition had progressed to where an acute obstruction and urinary tract infection required the use of an indwelling catheter and prolonged antibiotic therapy. When PSA testing became available in 1992, the initial reading I had was already 11.9. Over the ensuing years, while on Proscar (5 mg/d), my prostate decreased in size on palpation and there were no further obstructive symptoms. The only problem was the therapy did not diminish the PSA level, which continued to rise to the level of 18. A series of prostate biopsies performed in 1992, 1994 and 1995 were interpreted as only showing benign prostatic hyperplasia and chronic prostatitis. When a fourth series of biopsies were proposed in 1996, I vehemently objected and demanded that an endorectal MRI be performed. That procedure immediately disclosed the cancer that had eluded the urologists' needles. With a target to aim at, the next four needle sticks all showed adenocarcinoma, interpreted as Gleason 4+3=7.

In 1996 there wasn't an awful lot known about the long term survival of men treated with seeding and/or external beam radiation, so it was very easy to be convinced that surgery was the way to go. I was assured that complications such as urinary incontinence were "rare". Having the radical prostatectomy seemed not a big deal. The only problem was that I developed severe stress incontinence. Multiple visits to my urologist over the next several years were unavailing, and I ultimately developed my own collecting system which I continue to use successfully for the difficulty. The good news, according to my urologist colleague and friend, was that the cancer had been completely removed, the surgical pathology was interpreted as a 3+4=7 cancer and my post-operative PSA was 0.1. **(Continued on page 7)**

♦ INSIDE THIS ISSUE ♦

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♦ FROM THE EDITOR'S DESK ♦

The newsletter normally presents the summary remarks of our last quarterly speaker. Wintry conditions caused us to cancel the February 7, 2007, presentation by Dr. Stephen A. Brassell. It has been rescheduled for May 2. Please see the item below for the details. Fortunately, we have two first person accounts that you should find interesting. Dr. C. M. Papa provides a unique insight into how a medical doctor coped with his diagnosis of prostate cancer. He has some pertinent advice for men dealing with the disease. Next, Gerry Early recounts his experience with robotic laparoscopic surgery. The relatively new surgical procedure is attracting more men to select the latest technology over the conventional open prostatectomy. As noted below, Dr. Brassell will address this very subject on May 2.

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The Department of Defense Prostate Cancer Research Program (PCRP) is again seeking volunteers (prostate cancer survivors and advocates) to serve on peer review committees to help evaluate scientific research proposals that will help eradicate prostate cancer. This is an important effort worthy of your consideration, but time is short. See page 14 for more details.

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♦ PROGRAM FOR WEDNESDAY, MAY 2, 2007 ♦

Major Stephen A. Brassell, MC, is our speaker for Wednesday, May 2, 2007. He is Assistant Director of Clinical Research Programs and a Urologic Oncologist at the Center for Prostate Disease Research at WRAMC. His topic is "A Just Technology or Just Technology: Robotic versus Open Prostatectomy." Given the heightened interest in the Da Vinci Robotic System, Dr. Brassell's comparison of it with the conventional open prostatectomy should prove interesting. Join us at 7 PM on Wednesday, May 2, 2007, in Joel Auditorium. Plan now to attend and bring your spouse or a friend.

Prostate Cancer Mortality in Black Men. Talcott, et al., Massachusetts General Hospital Cancer Center, cite the lack of access to healthcare as the more important factor in the greater prostate cancer mortality seen in black men than is any lack of knowledge about the condition. Annual prostate cancer mortality in recent years was 68.1 per 100,000 African-American men, compared with 27.7 per 100,000 for Caucasian-American men. The disparity was even more striking in North Carolina, with corresponding figures of 77.9 and 28.5. The researchers surveyed 207 black and 348 white North Carolina residents recently diagnosed with prostate cancer. The African-American men were younger, had less education, and lower job status and income than Caucasian men. However, they were aware of their increased risk of cancer, the importance of treatment, and their responsibility for their health. Obstacles to timely diagnosis and appropriate care included greater physician distrust, reduced access, and continuity of medical care due to their worse socioeconomic position. The researchers concluded that to increase African-American men's use of prostate cancer screening, get earlier diagnosis, and increase their trust in physicians requires addressing medical insurance gaps, ensuring that routine care occurs in convenient settings with a regular physician instead of walk-in clinics and emergency room care, and protection against workplace penalties for getting medical examinations. (Source: *Cancer* 2007;109 via Reuters Health Information, March 21, 2007)

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Watchful Waiting/ Active Surveillance Under-utilized. Before the introduction of PSA testing in 1987, the majority of prostate cancer was diagnosed at stage C or D and often had already spread beyond the prostate. Five years after the test was introduced, there was a marked change, with 95% of cases diagnosed at stage A or B, where the disease is still localized and is curable. Barocas, et al., from New York Presbyterian Hospital and Weill Medical College of Cornell University, found that 16% of men studied were candidates for active surveillance, or watchful waiting, but only 9% chose this option. The findings suggest that active surveillance is an underutilized strategy for managing patients with very low-risk prostate cancer. (Source: Multidisciplinary Prostate Cancer Symposium: Abstracts 292-30, presented February 22, 2007; via Medscape Medical News, March 2, 2007)

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Androgen Deprivation Therapy Triples Risk of Periodontal Disease. Famili, et al., University of Pittsburgh, found that men with prostate cancer who are undergoing androgen deprivation therapy have a more than three-fold increased risk of periodontal disease compared with their counterparts who are not on androgen deprivation therapy. .Men on hormonal deprivation therapy should be referred to a periodontist for follow-up during this phase of treatment, the investigators said. Periodontal disease also was assessed in relation to bone mineral density. However, there was no link found between bone mineral density and periodontal disease. The researchers suggest that this relationship between hormonal therapy and periodontal disease could have important public health implications, given the increasing use of androgen therapy to treat prostate cancer. (Source: *Urology* 2007;177:921-924, via Reuters Health Information, March 3, 2007)

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PSA Density May Be Key to Biopsy Decision. Physicians may soon be able to identify which men have a more deadly form of prostate cancer. More than one million prostate biopsies are performed each year. Of these, only 25 percent test positive for cancer, but another 25 percent

have false negative findings, which means the test comes back negative even though it is later found that the patient does have cancer. New research may help identify which men need a second prostate biopsy after an initial negative biopsy say researchers at the Portland Veterans Affairs Medical Center**.** For their study, the researchers studied 511 men at the veterans' center who had been referred to urology clinics for suspicion of prostate cancer. All of the men had a prior negative biopsy. The researchers found that a high prostate specific antigen (PSA) level adjusted for prostate size was an indicator for repeat biopsy. Pinpointing patients who need a second biopsy will not only help identify which men may have a deadly form of prostate cancer, but it could also reduce the rate of unnecessary biopsies. This is important, since prostate biopsies are costly and can result in anxiety, pain, bleeding and infection. (Source: HealthDay News, March 22, 2007)

Age Adjustment of PSA Measures May Improve Prostate Cancer Screening. Moul, et al., Duke University Medical Center, say that current biopsy thresholds for prostate specific antigen (PSA) and PSA velocity underestimate prostate cancer risk in younger men. The researchers studied data on 11,861 men who had had two or more PSA tests within 2 years. They say their study shows, for the first time, that the diagnostic criterion currently used to indicate prostate cancer in all men needs to be age-adjusted in order to more effectively detect the cancer in younger men under 70. In other words, in younger men, smaller rises in PSA predict cancer while in older men, larger rises indicate cancer. The researchers found that the criterion -- how fast the level of prostate specific antigen (PSA) is rising -- needs to be set at a lower threshold for men under 70. According to the analysis, PSA levels grow more slowly in men under 70, making 0.75 ng/ml/yr an inadequate benchmark when trying to decide whether to proceed with a biopsy in a younger population. Instead, the new optimal age-adjusted threshold for men under 60 is 0.4 ng/ml/yr, and for men between ages 60 and 70, it is 0.6 ng/ml/yr. The current threshold is an accurate predictor for men at or above age 70. (Source: *J Urol* 2007;177:499-504,426-427, via Reuters Health Information, February 15, 2007)

Prostatectomy Procedures and Incontinence. Canadian researchers report that there is no significant postoperative difference in the rates of urinary incontinence between open radical retropubic prostatectomy and laparoscopic radical prostatectomy. Jacobsen, et al., University of Alberta, Edmonton, note that laparoscopic and robotic prostatectomy have become popular based on improved visualization, meticulous dissection and shortened convalescence. Critics of the laparoscopic technique question its oncologic efficacy and functional outcomes. Numerous studies have demonstrated that the laparoscopic technique provides comparable perioperative outcomes relative to the open approach in regard to postoperative blood loss, transfusion, analgesic requirements, hospitalization and convalescence. The researchers analyzed the data from 172 patients treated with open radical prostatectomy and 57 who underwent the laparoscopic procedure. All had clinically localized prostate cancer. At one year, 13% of those who underwent the open procedure remained incontinent compared with 17% of those who underwent laparoscopic prostatectomy - a nonsignificant difference. There was also no difference between groups in measures such as 24-hour urinary pad wear and urinary symptom scores. The incidence and severity of incontinence 12 months postoperatively was similar between the two surgical groups. Based on this study, the researchers say that patients who select surgery can be assured that the postoperative continence rates of laparoscopic prostatectomy are at the very least equivalent to that of open radical retropubic prostatectomy. (Source: *J Urol* 2007;177:615-619 via Reuters Health Information, February 14, 2007)

Prostate Cancer Costs Vary by Treatment Type. The total cost of prostate cancer treatment varies significantly by treatment type. The initial costs of a prostate cancer treatment are not reflective of the full cost over time of the treatment and, therefore, should not be used to determine the best choice of treatment for a patient or in decisions of treatment insurance coverage. Wilson, et al., University of California, San Francisco, compared patterns of healthcare utilization and direct costs of prostate cancer-related treatments over a 5.5-year period in 4,553 newly diagnosed patients, stratified by age, risk group, and ethnicity. In the first 6 months after diagnosis, average direct prostate-related costs per patient were high ($11,495) and highly variable ($2,586 for watchful waiting to $24,204 for external-beam radiation therapy). After the first 6 months, average prostate-related costs were only $3,044, ranging from $2,418 for radical prostatectomy to $6,019 for androgen deprivation therapy. Cumulative costs for the entire period were highest for androgen deprivation therapy ($69,244) and external-beam radiation therapy ($59,455) and lowest for watchful waiting ($32,135) and brachytherapy ($35,143), the researchers note. The most costly treatments were generally employed for the highest risk groups, whereas the least costly treatments were used for the lowest risk groups. The researchers conclude that prostate-related costs per person are substantial and sustained over time and that short-term treatment cost comparisons most commonly found in the literature do not truly reflect the cost of treatment choices over the long term. (Source: Cancer 2007, via Reuters Health Information, December 21, 2006)

Prostate Cancer Treatments May Affect Penile Length. First it was the radical prostatectomy, now it gets worse! As a treatment for locally advanced prostate cancer, hormone therapy plus radiation is associated with a significant reduction in penile length, according to a recent report in the Journal of Urology. There was anecdotal evidence that radiotherapy may reduce penile length, but the present study is the first to determine if penile length changes following treatment with hormone therapy plus radiation. The study involved 47 men who received leuprolide or goserelin injections every 3 months for a total of 3 injections. At month 7, radiotherapy (total 70 Gy) was initiated and continued for 7 weeks. The average stretched penile length at baseline was 14.2 cm (5.6 inches). At 18-month follow-up, the mean length had dropped significantly to 8.6 cm (3.4 inches). Erectile function was also adversely affected by treatment. Roughly 23% of men had normal erectile function before therapy. At 18 months, the percentage with erections suitable for intercourse fell to 12.5%. Quality of life concerns are important when considering treatment options for prostate cancer, so patients should be counseled before this therapy (neoadjuvant hormonal therapy and external beam radiation therapy) that penile shortening may occur. (Anyone for watchful waiting?) (Source: J Urol 2007;177:128-130, via Reuters Health Information, January 11, 2007)

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Prostate Cancer Deaths Down 15% for African-Americans, But Gap Persists. Death rates from cancer have been declining among both African-American men and women, according to American Cancer Society report: Cancer Facts & Figures for African Americans 2007-2008. For African-American men, prostate cancer deaths are projected to drop 15.4 percent over two years, with an estimated 5,050 deaths in 2005 and an estimated 4,240 deaths in 2007. Actual incidence rates for African-American men are trending downward, averaging 258.3 per100,000 men in the period from 2000-2003, down 5.8 percent from an average of 274.3 per 100,000 men from 1997-2001. Actual death rates for African American men have also been dropping, averaging 64 per 100,000 men in the period from 2000-2003, down 9 percent from an average of 70.4 per 100,000 men from 1997-2001. While rates are declining for both, prostate cancer rates for African-American men remain

far higher than their white counterparts, with the ratio of prostate cancer incidence rates remaining 1.6 times that of white men, and the death rate remaining 2.4 times that of white men. (Source: *Cancer Facts & Figures for African Americans 2007-2008*; American Cancer Society)

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High-Intensity Focused Ultrasound Effective Against High-Risk Prostate Cancer. High-intensity focused ultrasound (HIFU) safely provides favorable short-term outcomes in men with high-risk prostate cancer, according to a recent study. Ficarra, et al., the University of Verona, Italy, investigated the short-term outcome of HIFU treatment in 30 patients with high-risk prostate cancer who had all previously undergone transurethral resection of the prostate (TURP). HIFU was administered under general anesthesia, and the men received concomitant hormonal therapy. No complications were reported during HIFU, which required a median overall duration of 140 minutes. The mean hospital stay was 2.2 days. Symptomatic lower urinary tract infections were reported in 5 patients during the first year, and 3 patients experienced urethral stenoses (constriction). Three months after HIFU, 25 patients had complete urinary continence, and all but 2 patients (78 and 79 years old) were continent after 12 months. Six months after HIFU, the median prostate volume was significantly lower than the baseline value, the report indicates. Sextant prostate biopsy was positive in 7 patients (23%), including 4 with one positive core and 3 with two positive cores. None of the patients had PSA values above 1.0 ng/mL at 1 year, the investigators say, and only 3 patients (all of whom had two positive cores at the 6-month sextant prostate biopsy) had PSA values above 0.3 ng/mL. The researchers note that in the event of recurrence, it is possible to repeat HIFU local treatment, although complication rates could be higher than those at the initial treatment. HIFU still needs to be evaluated regarding its long-term oncological results. The researchers conclude that HIFU is based on a focused form of energy providing higher safety and precision than divergent energies (cryotherapy, radiotherapy); in patients with a high risk for progression or with locally advanced disease, this treatment might represent a valid alternative to radiotherapy. (Source: *BJU International* 2006;98:1193-1198, via Reuters Health Information, January 11, 2007)

KNOW SOMEONE NEWLY DIAGNOSED WITH PROSTATE CANCER? DIRECT HIM TO THE WEB SITE OF THE CENTER FOR PROSTATE DISEASE RESEARCH AT WWW.CPDR.ORG. IT HAS MUCH USEFUL INFORMATION. HE CAN FIND THE CURRENT ISSUE AND BACK ISSUES OF THE WRAMC NEWSLETTER AT WWW.CPDR.ORG/PATIENT/NEWSLETTER.HTML.

(Prostate Cancer Survivor – Continued from page 1)

Happily doing nothing for myself for the following four years, except managing my urinary incontinence, there were no worries until the PSA suddenly jumped to 0.2. Now retired and living away from my old haunts, I visited a nearby, new urologist.

He correctly asked for a written summary of the hospitalization. It was something I had foolishly neglected to secure. After all, my urologist had assured me that he had removed everything, and I was "clear". Imagine our surprise when the surgical pathology noted remaining tumor at the excision margin, and that in his discharge summary, the urologist not only acknowledged this, but there was the written recommendation that I immediately receive salvage radiotherapy. I confronted the original urologist about the discrepancy, and he answered, "Well, you are OK clinically and your PSA is only 0.2." There was some truth in that and, in retrospect; not knowing about the facts had provided me with four rather carefree years, a blessing, indeed.

Now a decision was made to visit a prostate cancer oncologist at a well-known large specialty center. Although there were a bunch of clinical studies under way, my low PSA disqualified me and I was offered a choice of either salvage radiation or hormonal blockade. Learning that these options have problems of their own, I turned them down. Interestingly, over the next year and a half all that was done were quarterly endorectal MRIs, which clearly showed a 1.0 cm tumor at the site where the cancer had been left in the original surgical procedure.

As my PSA slowly started rising up to 0.34, I decided that non-treatment might not entirely be adequate, and sought out another old colleague, a medical oncologist who I knew to stay current with advances in his specialty. He was sympathetic to my choice not to have either the hormone therapy or salvage radiation, and in 2002, we agreed to see how a combination of 400 mg Celebrex and 0.5mcg calcitriol would influence my rising PSA. On careful physical exam I continued to be clear, but the PSA continued its slow rise. We then doubled the dose of both drugs and they seemed to cause the PSA to plateau to a level about 0.4, where it remains at present.

Interestingly, there have been three times over the past three years when I had to temporarily discontinue my cancer therapy; for an emergency gall bladder removal, for a right hip replacement, and prior to a colonoscopy procedure. In each instance, my PSA jumped up to about 0. 56, then slowly dropped back to 0.4 after I resumed treatment. The initial dosage adjustment and these interruption episodes seem to prove that the combination of drugs is just sufficient to keep my recurrent cancer under control and the PSA quite level.

My "complementary therapy" over the years has been a balanced heart-healthy diet that pretty much avoids beef, the addition of soy foods, lots of tomato sauce and juice for the lycopenes, pomegranate juice, turmeric and 200 mcg of selenium. I take a statin for my hyperlipidemia, which may also help. I exercise regularly, and do a lot of joyous singing with a barbershop group, participating in the large chorus, a smaller day chorus and in quartets. When I last saw my oncologist, I pointed out to him that over the past four years under his care, my PSA had only progressed from 0.34 to 0.46. He took out his pen, figured out my PSA doubling figure and announced with a smile that he wouldn't have to worry about me until I was 230 years old. He's my kind of doc! **(Continued on page 8)**

Is there a moral to my story, or lessons to be learned? First, never accept verbal reports of anything that is happening to you. If one physician can hide facts from another, what chance do you have of learning the truth? Always insist on the full written report of all lab work and procedures, as well as hospitalization summaries. I also request and receive the consultation notes my oncologist sends to the other physicians who care for me. Secondly, there is no substitute for learning all you can about the basics of your condition as well as the upside and downside to the treatment options. You must be responsible for guiding your care.

Each patient is unique and cookie cutter solutions are not the way to go. I know that the initial oncologist I saw was unhappy with me because I wouldn't accept either of the limited options that were offered to me. So what? It turned out to be a good decision for me. I persisted and received really novel therapy that seems to be helping me, and hasn't bothered my quality of living. Finally, lead a good healthy life and take care of all the other problems. They're the ones that are more likely to be fatal, long before the prostate cancer ever is. **(Editor's note**: This is Dr. Papa's second contribution to the newsletter. His first dealt with his experience in coping with incontinence.)

Inflammation May Play Role in Metastasis of Prostate Cancer

Many would assume that "mounting an immune response" or "having your body fight the cancer" is a good thing. Now, recent research by Karin, et al., University of California, San Diego School of Medicine, strongly suggests that inflammation associated with the progression of tumors actually plays a key role in the metastasis of prostate cancer. The research may also have application to breast cancer metastasis.

A major hypothesis in cancer research has been that whether the cancer metastasizes or not is determined by genetic changes within the cancer cell itself. But this hypothesis didn't explain why metastases appear many years after the initial tumor. This new research may help solve the puzzle of why it takes so long for cancer to metastasize, as well as what causes it to do so. It also may lead to development of anti-metastatic therapies.

The findings suggest that promoting inflammation of the cancerous tissue – for instance, by performing prostate biopsies – may, ironically, hasten progression of metastasis. The researchers say they have shown that proteins produced by inflammatory cells are the 'smoking gun' behind prostate cancer metastasis. The next step is to completely indict one of them. The study helps explain the paradox that, in certain types of malignancy, inflammation within a cancer may be counterproductive. (Source: University Communications Office, University of California, San Diego; March 19, 2007)

(**Editor's note**: This new research was supported in part by the Prostate Cancer Research Program (PCRP) within the DOD Congressionally Directed Medical Research Programs. See page 14 to learn how you can participate in this important effort.)

♦ A ROBOTIC PROSTATECTOMY - MY EXPERIENCE ♦

by

Gerry Early

Introduction

During the past two years I have traversed a path that took me from prostate cancer victim to prostate cancer survivor. Understandably, this process has been a principal focus of attention, so I read considerably and spoke to a number of knowledgeable people about the topic. The treatment I underwent, robotic laparoscopic prostatectomy, is comparatively new, so much of the abundant information available on the conventional radical prostatectomy did not apply.

I therefore decided to write this summary of my experience for the benefit of newly diagnosed men who may be considering the robotic laparoscopic prostatectomy as their primary therapy. Obviously, I am no medical expert, so my personal experience could vary from other men in significant ways.

From start to finish this experience with prostate cancer was a joint enterprise with my loving and supportive wife. She was in on all the key meetings, had a full voice in all decision-making, and pitched in fully in the messy business of the post-surgery period of home recuperation. We have a sense of proportion that helps us understand that, while prostate cancer is a very bad thing indeed, it is does not even remotely compare with the medical situations faced by many others such as victims of major calamities. As a result, neither of us has a high regard for sniveling or self-pity, and on those occasions when I began to get wobbly in this regard, she was quick to tighten me back up.

Getting the Diagnosis.

Beginning about age 54, I had problems with prostate enlargement and periodic flare-ups of prostatitis that were resolved with six-week treatments of Cipro. In 1998, we moved from the Washington, DC, area to the Eastern Shore of Maryland, where I found a new urologist for regular annual exams including PSA tests.

In 2003, my younger brother was diagnosed with prostate cancer at age 60. When I had my periodic urology examination in summer 2004, my PSA had increased from 1.8 to 3.2 over the preceding three years, so I asked about a biopsy. The urologist ordered a free PSA test, and results were satisfactory, but he agreed to change my PSA tests from an annual to a semi-annual schedule. In the early fall I had a regular annual physical examination with my internist in Washington, which found a PSA of 3.5. I reported this to the urologist, who reluctantly agreed to perform a biopsy.

In November 2004, at age 67, I was diagnosed with prostate cancer. My wife and I visited the urologist who did an excellent job of explaining the biopsy results, my Gleason score of 6, my overall medical situation, and two treatment options: radical prostatectomy or some form of radiation therapy. He also ordered a bone scan for me at our local hospital, which fortunately disclosed no evidence of prostate cancer spread. He knew that I was a retired military man with the possibility of being treated at Walter Reed Army Medical Center or the Naval Medical Center, Bethesda

I immediately went to the library and took out *Dr. Patrick Walsh's Guide to Surviving Prostate Cancer*,which is simply excellent. I also read two other books which, frankly, did more harm than good (especially *Man to Man* by Michael Korda). Based on "Where to Get Help" in Dr. Walsh's book, I looked up various websites on prostate cancer and even ordered a boxful of materials on making an informed decision. For many years, because of my prostate enlargement situation, I have been receiving the quarterly

newsletter of the American Prostate Association. As a result, I was already fairly knowledgeable of many aspects of the disease and its treatment.

Next my wife and I conferred with our internist in Washington who had our confidence. We asked him what he would do if he were faced with my situation. He said that undoubtedly he would go to the Johns Hopkins University, a world leader in the treatment of prostate cancer, and a place where the less-intrusive laparoscopic and robotic technique for prostatectomy is available. A visit to the Johns Hopkins website resulted in a call that was nicely handled by the receptionist. After I provided my age, PSA, and Gleason score, she offered a list of six surgeons with whom I could request an appointment. After reviewing their impressive credentials, we made a selection influenced by the fact that he performed more than 100 such operations each year.

Decision

In mid-November, my wife and I went to JHU. I completed additional patient history forms and provided insurance information. Then we met with the urologist who obviously read my patient history in advance. After he performed a digital rectal examination, he posited three treatment options, none of which he strongly recommend over the others. These were watchful waiting with a follow-up check every six months, radiation (but not seed implant because of my prostate enlargement), and surgery.

In considering the options, I dismissed watchful waiting because if I truly had cancer I want something done about it--definitively and promptly. Also, JHU will not do prostate cancer surgery after age 70, so in less than three years that option would have disappeared if watchful waiting eventually disclosed progression that warranted action. I didn't favor radiation because it takes about two months of five-day-a-week treatments. We live too far from JHU to make the radiation feasible, and I would not consider having such delicate work done at our local hospital. I opted for surgery because all my research indicated it was the one technique with a proven record that could result in a permanent cure if done in time, while the long-term results and expectations after radiation were much less clear.

The doctor explained that two types of surgery were available. The first was the traditional radical prostatectomy, which takes about an hour and a half to perform, but is more intrusive and has a far longer recovery period. The other was laparoscopic or robotic prostatectomy, much less intrusive, whose procedure takes over four hours, but recovery from it is much quicker. The expected outcomes were the same in either case. Laparoscopic prostatectomy it would be! We had many personal commitments in the months ahead, but the doctor said some delay would make absolutely no difference. So we scheduled the surgery for the morning of Thursday, March 10, with a pre-operative evaluation on the afternoon of March 9.

The surgery could have been scheduled as soon as 4-6 weeks after this visit and with benefit of hindsight, this would have been a wiser choice. I say this for two reasons: my post-operative Gleason score was 7, so the cancer was worse than expected, and the much shorter recovery period from robotic surgery would have allowed the operation in early January and the personal activities as originally scheduled. In retrospect, I think delaying for two or three months was playing with fire, although I came through it without penalty.

Pre-Operation

I left JHU with another packet of instructional materials, additional patient history forms, a variety of consent forms, and instructions for the pre-operative process. Also included were well-written information sheets on what to expect prior to and after surgery--but unfortunately the

after-operation information pertained only to the conventional procedure and not the laparoscopic prostatectomy. The urologist offered a list of past patients whom he had successfully treated, but it turned out that the only names provided were for people who had the conventional radical prostatectomy, whose observations were only marginally useful.

On March 9, a day without solid food and only clear liquids, I reported to JHU for the pre-operation evaluation, completed additional forms for patient history and insurance, and had another mini-physical exam by a physician's assistant. The whole process took about two hours and was efficiently handled. My wife and I stayed at a hotel in Baltimore on the evening of March 9. As instructed, I gave myself a Fleet Enema about an hour before going to the hospital on the following morning.

Surgery

As with everything at JHU, the check-in was quick and efficient. Shortly afterward I was brought into a pre-operation area, and during the next half-hour, an IV was installed. Then I was visited by various medical staffers, among them the doctor-and-nurse anesthesia team. After 8 am, I was wheeled to the operating theater and within moments thereafter it was lights-out. The procedure took four and one-half hours. Afterward, the doctor visited my wife in the waiting area to say that all had gone well.

The Aftermath

Afterward I was moved to the hospital room in Marbury Pavillion where I had requested a private room. I woke with so little pain then and thereafter that I never felt the need to press the pain medication button. My wife was in the room and my recollection is that I was chatting in a normal fashion, but she says I was groggy all evening. The next day I couldn't recall some of what was discussed.

I slept fairly comfortably through the night, with the medical staff checking periodically for IV and other adjustments. I was brought a very light breakfast consisting mainly of liquids. I'd read there would be little hunger for the first couple of days, which was indeed the case, so all I had was a couple of spoonfuls of the cereal, the juice and coffee.

A team of young doctors visited about 8 am, and the chief resident asked the nurse to get me up and walking. She walked with me the first trip down the long hallway, with the IV stand between us, and for the remainder of the morning I walked on my own without difficulty. The chief resident said it was possible that I could be discharged that day if I so wished. My urologist came in later to say that the surgery had gone well and my recovery seemed excellent. He confirmed that I could go home that day and my wife and I instantly agreed. He gave instructions for follow-on care, saying that the catheter should be removed ten days after surgery.

At this point, and for a couple of days thereafter, there was some aching although no real pain in my abdomen, but just enough discomfort that I tended to bend over a bit when walking. The only difficulty I had at this point was that my walking seemed to over-stimulate my bladder, causing a spasm which resulted in a spurt of urine beyond what was going through the catheter. After a couple of days the spasm feeling ended, but for the remainder of the time with the catheter there was serious overflow whenever I moved around much. The nurse showed us a videotape on taking care of the catheter system, then provided a package of dressings and absorbent pads and other equipment to provide for various unpleasant contingencies. We left the hospital in mid-afternoon for the one-hour trip from Baltimore back home. I was offered and accepted pain medication to be sure I wouldn't be uncomfortable during the car trip.

Recovery

At home I still didn't have an appetite for food, but I knew it was essential to drink a lot of fluids and I did so. I had no real pain, but I was ultra-careful in getting out of a chair and walking up and down the stairs. For the first week I slept in an upholstered recliner in our bedroom to ensure I wouldn't roll around and have catheter trouble during the night. This was probably unnecessary, but it worked out fine.

Throughout the ten-day period until it was removed, the catheter was a nuisance because of a continuing overflow problem. My wife covered herself with glory in helping me with the minimum twice-daily cleanups and in working through various possibilities for attempting to control the urine overflow. After two days she bought a package of Depends which solved the problem. Soon I was really able to take care of myself including showering, twice-daily cleaning, and servicing the catheter bag.

I might mention that at first the contents of the catheter bag were alarmingly dark and bloody, but since nobody at the hospital found that unusual, we knew it was not a problem. After a week, the urine was clear, light, and natural looking. I was concerned about possible problems with bowel movements. For the first few days the product was watery, then it became something more like diarrhea. After a few days, I was eating normally, and by the end of a week the stool was normal and regular.

Two days after the operation, I walked the quarter-mile to the road to get the newspaper in the morning, the mail at midday, and took another walk later in the day. Then I started taking at least one long (three-mile) walk and one or two shorter trips daily. Also, I was able to work on the computer for hours each day. Soon I was able to get into town to visit the library, post office, grocery store and frequent our favorite restaurants. My local urologist removed the catheter with no difficulty on March 21. To my distress, however, I had "zero" bladder control, so I had to continue my reliance on Depends.

Follow-on Actions

There are two checkpoints after surgery that confirm the efficacy of the operation. The first is the pathology report and second is the initial postoperative PSA test. On March 16, the doctor called with the welcome news that the pathology report provided the best-possible outcome of "organ confined." Nevertheless, the final Gleason rating was 7, which came as a surprise.

My JHU urologist said only about 10 percent of patients have immediate urinary control upon removal of the catheter. He urged patience and the recommended Kegel exercises, assuring me there would be improvement. Only a small percentage of cases do not resolve themselves, requiring further surgery or other medical solutions. He also reconfirmed that two weeks after surgery, I could resume my normal exercise activities. In retrospect, I think was too soon. Based on my experience, I would recommend something more like the traditional six weeks before returning to any serious exercise. On May 10, I had my first postoperative PSA test. The PSA reading was 0.01, about as low could be expected. Six months after surgery, a second PSA test had the same reading, and one year later, the results are the same.

Side Effects

<u>Incontinence</u>. This was a real problem for me, far worse than what I understood is the case for the typical patient. At first I had no control at all, but about three months after surgery there was steady improvement (down from 10-or-so pads to one pad). In September, I returned to Johns Hopkins to see my urologist for the

first time in the six months since my surgery. He suggested I try imipramine, an anti-depressant, but it also dries one out. I used it for almost a month with no improvement in incontinence, but it had annoying side effects, so I discontinued it.

I know that some men have good urinary control almost immediately, but for me the three-stage process described *in Dr. Patrick Walsh's Guide to Surviving Prostate Cancer* describes almost exactly how my recovery in this area has progressed.

Now two years after surgery, I am 95 percent dry, but still must wear a pad just to be sure. The leakage is when I jog or am otherwise very active. In fact, there has been little noticeable improvement in the past year, so I am afraid the precautionary pad may be a permanent condition.

Impotence. I had thought I'd be home free on this one, because of sensations I could feel even before I left the hospital. We didn't try this out until about two and a half months after surgery, largely because I wanted to allow time for all the plumbing to heal. To my disappointment, I have not been able to get an unaided erection, even with Viagra, Cialis, and Levitra, although I can have a soft orgasm. On the other hand, I am 69 and had used Viagra for about two years before surgery, so probably I'm not the greatest candidate for quick recovery.

When I returned to Johns Hopkins in September 2005, my urologist suggested I try penile injection therapy, by which one self-administers a drugby needle directly into the penis, causing an erection within 5-20 minutes. The product I used was Caverject, which allows a man to sequentially increase the dosage to the point where it works.

For the past year I have used the vacuum pump device that usually does the trick. As I gain more experience, it will become more effective. Unfortunately, after prostate surgery everybody does less well regarding erectile dysfunction. I have found that the vacuum pump is effective, and much more congenial than the self-administered penile injections. As I gain more experience with it, I think it will do the job

Summary

Would I do it over again? Yes! Once I had elected surgery, the laparoscopic procedure was the way for me to go. I liked the idea of the latest technology in competent hands, and the less invasive prospect that would allow more rapid return to resuming my regular activities. Admittedly, my experience with the side effects of incontinence and erectile dysfunction has been consistent with those commonly associated with the conventional open prostatectomy.

My ability to deal with prostate cancer was positively affected by my personal research and preparation, the loving support of my wife, and the accessibility of a first class medical facility and its staff. Finally, the newly diagnosed man must maintain a positive attitude throughout the entire process, from selection of therapy to coping with the likely side effects. A diagnosis of prostate cancer is not a death sentence; it is simply a new life direction that can be managed.

THIS NEWSLETTER IS MADE POSSIBLE BY AN EDUCATIONAL GRANT FROM ASTRAZENECA, MAKER OF CASODEX AND ZOLADEX.

A CHANCE TO SERVE, BUT YOU MUST ACT FAST!

Did you know there is an agency that wants you, yes, **YOU,** to help award $80 million during 2007 to scientists seeking a cure for prostate cancer? Well, there is and it is looking for volunteers (called Consumer Reviewers) to participate in what is called a peer review process – an orderly procedure that evaluates research proposals from scientists, universities, and research organizations that are seeking financial support for their efforts to combat the disease. Prostate cancer survivors and advocates like you serve on evaluation panels with distinguished scientists to recommend funding for the most worthy research proposals. And no, you don't need to be a PhD. to participate effectively. The scientist-reviewers analyze the technical aspects of the research proposals; you contribute your own firsthand experiences, the perspectives of your prostate cancer group, and a sense of urgency for eradication of prostate cancer. Your scientist colleagues will welcome your input to the evaluation process.

If selected, you will spend two days during July at a central location in the metropolitan Washington, DC area. Your travel, meals, and lodging expenses are paid and you receive a $1,250 honorarium. But this is not a freebie. You must prepare in advance by reviewing the research proposals assigned to your peer review panel, and then participate actively in the on-site evaluation process. You are not alone; an experienced Consumer Reviewer is also assigned to your review panel and he is available prior to and during the entire process to assist you in your preparation and participation.

The agency that wants you is the US Army Medical Research and Materiel Command charged by the US Congress to administer the Congressionally Directed Medical Research Programs that includes the Prostate Cancer Research Program (PCRP). Since 1997 the PCRP has provided $730 million for basic and clinical research, and there is $80 million available more for 2007. This is a magnificent effort and you can be a part of it.

Interested? Good! But you must act fast because your nomination must reach the PCRP by **May 14, 2007**. First, you must secure a nomination from your prostate cancer-related organization that then submits it to the PCRP for consideration. You should go to this web site: http://cdmrp.army.mil for general information about the PCRP peer review process and consumer involvement. To learn about the application process, go to http://cdmrp.army.mil/cwg/process.htm. If you do not have Internet access, contact the PCRP at (301) 619-7319.

You can make a difference in the fight against prostate cancer. Get involved with the PCRP!

♦ WRAMC US TOO COUNSELORS ♦ (AS OF May 1, 2007)

(These persons are willing to share their experiences with you. Feel free to call them.)

SURGERY

Tom Assenmacher	Kinsvale, VA	(804) 472-3853	
Jack Barnes	Oakton, VA	(703) 620-2818	
Jack Beaver	Falls Church, VA	(703) 533-0274	
Jerry Bussing	Laurel, MD	(301) 490-8512	
Gil Cohen	Baltimore, MD	(410) 367-9141	
Richard Dorwaldt	San Antonio, TX	(210) 310-3250	(Da Vinci Robotic Surgery)
John Fellows	Annandale, VA	(703) 503-4944	
Tony French	Annandale, VA	(703) 750-9447	
Michael Gelb	Hyattsville, MD	(240)475-2825	(Robotic Surgery)
Robert Gerard	Carlisle, PA	(717) 243-3331	
Ray Glass	Rockville, MD	(301) 460-4208	
Monroe Hatch	Clifton, VA	(703) 323-1038	
Tom Hansen	Bellevue, WA	(425) 883-4808	(Robotic Surgery)
Bill Johnston	Berryville, VA	(540) 955-4169	
Dennis Kern	San Francisco, CA	(415) 876-0524	
Steve Laabs	Fayetteville, PA	(717) 352-8028	(Laparoscopic Surgery)
Don McFadyen	Pinehurst, NC	(910) 235-4633	
James Padgett	Silver Spring, MD	(301) 622-0869	
George Savitske	Alexandria, VA	(703) 671-5469	
Artie Shelton, MD	Olney, MD	(301) 523-4312	
Jay Tisserand	Carlisle, PA	(717) 243-3950	
Don Williford	Laurel, MD	(301) 317-6212	

RADIATION

John Barnes	Springfield, VA	(703) 354-0134	(Intensity-Modulated Radiation Therapy)
Leroy Beimel	Glen Burnie, MD	(410) 761-4476	(External Beam Radiation)
Ron Gabriel	Bethesda, MD	(301) 654-7155	(Brachytherapy)
Irv Hylton	Woodstock, VA	(540) 459-5561	(Brachytherapy)
Harvey Kramer	Silver Spring, MD	(301) 585-8080	(Brachytherapy)
Bill Melton	Rockville, MD	(301) 460-4677	(External Beam Radiation)
Oliver E. Vroom	Crofton, MD	(410) 721-2728	(Proton Radiation)
John Waller	Yorktown, VA	(757) 865-8732	(Brachytherapy)
Barry Walrath	McLean, VA	(703) 442-9577	(Brachytherapy)

INCONTINENCE

Larry Schindler	Silver Spring, MD	(301) 649-5946	
Ray Walsh	Annandale, VA	(703) 425-1474	

HORMONAL

"Mac" Showers	Arlington, VA	(703) 524-4857	
Tony Bicknell	Springfield, VA	(703) 451-7517	

WATCHFUL WAITING

Tom Baxter	Haymarket, VA	(703) 753-8583	

CLINICAL TRIALS

Philip Brach	Washington, DC	(202) 966-8924	

SPOUSE SUPPORT

Kay Gottesman	North Bethesda, MD	(301)530-5504	

OTHER THERAPIES/MULTIPLE THERAPIES

Philip Brach	Washington, DC	(202) 966-8924	(External Beam Radiation)
Howard Bubel	Fairfax, VA	(703) 280-5765	(Cryosurgery, Hormonal, Sexual Function)
Arthur E. Clough	Kerryville, TX	(210) 896-8826	(Surgery and Radiation)
S.L. Guille	Sumerduck, VA	(540) 439-8066	(Surgery, Radiation, Hormonal)
Richard Leber	Chapel Hill, NC	(919) 942-3181	(Surgery, Radiation, Hormonal)

Charles Preble Annandale, VA (703) 560-8852 (Cryosurgery, Hormonal, Intermittent Hormonal)

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♦ MEETING ANNOUNCEMENT ♦

WEDNESDAY, MAY 2, 2007
7 PM

JOEL AUDITORIUM (SECOND FLOOR)
WALTER REED ARMY MEDICAL CENTER

♦ SPEAKER ♦

MAJOR STEPHEN A. BRASSELL, MC
Center for Prostate Disease Research
Walter Reed Army Medical Center

♦ TOPIC ♦

"A Just Technology or Just Technology: Robotic versus Open Prostatectomy"