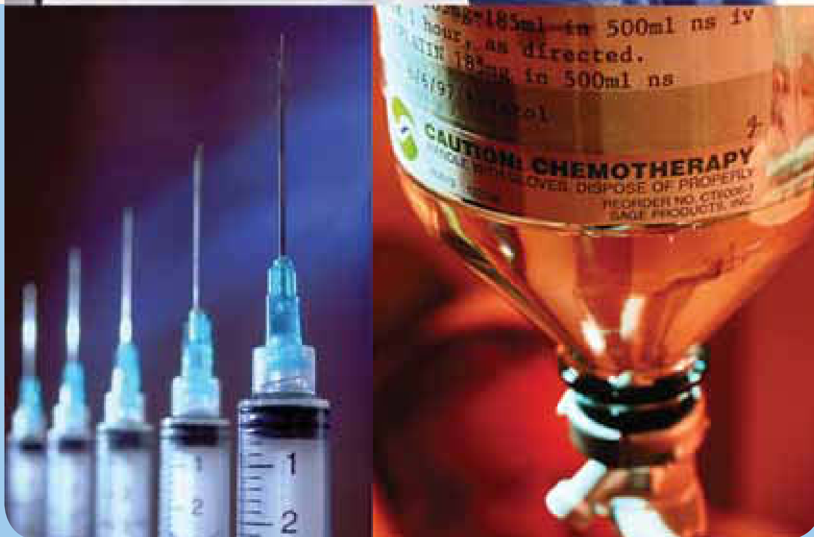
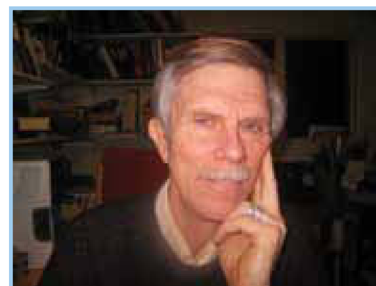
PROSTATE CANCER

Perspectives



On occasion, Insights will publish the first-hand accounts, observations and opinions of men who have been diagnosed with prostate cancer. The opinions that follow are those of the author and not necessarily those of the Prostate Cancer Research Institute.

Mark Lichty is a 60 yr old attorney and former CEO of Bustin Industrial Products. He has been on Active Surveillance for over four years, and hopes he may encourage other men to consider this path where appropriate. He is grateful to his group of Patient Pioneers who inspire him to continue on this path. This article is in memory of his father who died of prostate cancer.



By Mark Lichty

FIRST DO NO HARM — **ACTIVE SURVEILLANCE** May Be the *NEW* **GOLD STANDARD**

It is believed by some that we live in a time of over-intervention regarding prostate cancer (PC), and there is a slow but growing recognition by the medical profession that this may not always be in the best interests of the patient. In the world of prostate cancer, the time has arrived to truly abide by the principle of "first do no harm". Despite risk of side effects, and only slight improvements in life expectancy, the great majority of men diagnosed with PC will seek intervention, often ending up facing surgery, radiation treatment, and other common cancer treatments. *(Continued on Page 16)*

With PC it now appears to this author that in many cases less is more. Less intervention may mean better quality of life without significantly diminishing life expectancy. We assume that our doctors have a duty to refrain from doing harm. However, in a world where patients have access to nearly as much information as doctors do, patients need to shift from their passive role to one of active questioning participation. Let's take a backwards look to see the context in which I make this reduced intervention recommendation.

It was hard to watch prostate cancer take its toll on Dad. He first learned of the cancer when he was 70. He was radiated, which impaired his lymphatic system and caused fluid to collect in his leg. To correct that unforeseen effect, he was given a sleeve to pump the fluid back up his leg–an exercise in futility. That situation, combined with his castration, caused dad's spirits to falter. Struggling against these ravages, he passed over in 1996 at the age of 76, bravely counseling me on his deathbed, "It is all about attitude Mark." Even in his physical absence, he had a profound effect on my decision to choose active surveillance. Thanks Dad.

It was with this backdrop that my wife, Wendy, and I received the news in Dec. 2005 that I had been diagnosed with prostate cancer. The news was terrifying, as I had watched the inelegant demise of my father as he wrestled with PC. Now looking back over four years later, having chosen active surveillance (AS) as my "treatment", I realized that my anxiety was misplaced – misplaced but totally understandable. In 2005 I had not even heard of AS. Watchful waiting was the term applied, but that sounded to me like I was waiting to die.

My anxiety too was fueled by the fact that four medical professionals with over 120 years cumulative experience all were recommending that I undergo a radical prostatectomy, the gold standard at that time. Meanwhile, I was thinking of my father's PC carnage, and thinking of known side effects like incontinence, erectile dysfunction, etc. Furthermore, I was unconvinced that the prostate might not perform some other function that we don't yet understand. It was likely a silly notion, but I thought of the wholesale removal of tonsils and appendices in years past when they were assumed to be useless organs. I could not accept the doctors' recommendations. It was a tough road where I found little support. I found myself at times the object of pleas to consider a more mainstream approach, and of ridicule for not following a medically accepted course that had a more "scientific" basis.

I recall that when I was about a year into the journey, I spoke to my Unitarian fellowship about why I had chosen this path. There was a host of folks trying their best to caringly convince me to seek traditional intervention. Self doubts about my decision manifested along the way. These doubts found further acknowledgment when about a year into this I received an e-mail from a caring doctor who informed me that he had just lost a patient to prostate cancer, and that I should strongly consider some intervention of some sort.

I would like to say a word about Erectile Dysfunction (ED) and incontinence. Some level of ED and incontinence happen to a significant number of men treated for their prostate cancers. We still see men who a year or two following their treatments suffer from ED. To me, a man of 55, these were very significant side effects. These side effects went to the core of my dignity. I think we males place too much emphasis on our ability to pee and ejaculate properly, but that seems to be how we are wired. When I go to Us TOO prostate cancer support groups I hear men who have experienced these side effects bearing up under it, but I wonder if it was a price they had to pay. Many of these men when asked by the group say that they believe the risk of side effects was understated.

I am grateful to my urologist because he understood who I was. Initially he commented, "You are 55, and at that age I would recommend a radical prostatectomy (RP)"; but when told him that I wouldn't do that, he said, "I suspected that Mark. Here is the name of a patient who has taken the nutritional route, and you can contact him if you like." I did and that started my journey.

I refer to the period surrounding my Dad's encounter with PC as the "blunt instrument" phase of prostate cancer treatment: eliminate the cancer at all costs – sometimes using primitive technology. This phase

Low Risk Disease (Perfect 10)
Bahn's Criteria for Active Surveillance

1. Gleason 6 or less, may be up to 7=3+4
2. PSA less than 10 ng/mL (PSA Density < 0.15)
3. Stage: T1c -T2a, T2b with co-morbidity
4. Positive Biopsy Cores: less than 1/3 of cores
5. Percentage of tumor invasion: less than 50%
6. PSA doubling time: > 2 yrs, prefer >3 yrs.
7. Tumor neovascularity on color-Doppler: 1+ or less
8. Tumor volume on CD-TRUS: less than 1cc
9. Urine PCA-3 gene test: less than 35 (Tumor < 0.5cc)
10. Ploidy: Diploid

gave way to the era of technological advances; for example, the da Vinci method allowing improved prostatectomies, advances in imaging allowed for better methods of identifying the cancer's location for more precise treatment, etc.

In fact, in the past four years, since I was diagnosed, I have seen improvements in procedures, and somewhat reduced side effects, and remain hopeful for a future time when interventions for prostate cancer in fact may "do no harm". We seem to be entering the stage where a doctor and a patient are permitted breathing room and intervention only where it is called for, rather than intervention as an initial knee-jerk reaction. In fact, the National Comprehensive Cancer Network (NCCN), concerned about over-diagnosis and over-treatment, recently issued an advisory recommending that Active Surveillance be considered for low risk patients.

Some progressive organizations like the Prostate Cancer Research Institute (PCRI) and the Prostate Institute of America have led the path into the "do no harm" era. At least these groups are willing to discuss the possible existence of a "low risk" group of prostate cancer patients who may not benefit from drastic treatment immediately upon diagnosis. Why diminish the quality of these patients' lives by risking intervention and its side effects? Part of the explanation, I believe, is the lack of knowledge and perhaps confidence in the currently available methods for monitoring the status of prostate cancer. Patients and urologists just aren't yet comfortable. What would it take for AS to be embraced by urologists?

Returning to my journey, one of the challenges of choosing AS was the monitoring method. How would I know if the tumor was growing? How can I tell ahead of time if it might metastasize? I can remember early on sweating over these questions. The PSA test seemed to be a bit of a blunt instrument. In 2004, Dr. Stamey of Stanford University said the age of PSA is over [1] and that PSA is merely a reflection of the size of the prostate. I don't quite agree that its usefulness has passed, so I continue with my PSA tests. I also have done an annual Magnetic Resonance Spectroscopic Imaging (MRSI) test, which gives me an image of the size of the tumor. Seeing the image and reviewing the results with Dr. John Kurhanewicz at UCSF helped to alleviate my anxiety about my then uncertain path.

I had been doing my annual MRSI at UCSF – as they pioneered the process – and Dr. Kurhanewicz is deeply committed to getting the most out of this tool that he can. However, I am not thrilled with the endorectal probe that is inserted into one's rectum. Other monitoring methods exist, most notably the Color Doppler Ultrasound (CDU) which is designed to identify where angiogenesis (blood flow feeding the tumor) is present.

This year I traveled to Ventura, California to have the CDU done by a progressive and masterful radiologist and a strong proponent of AS, Dr. Duke Bahn. Dr. Bahn may be considered a maverick by some, but I suspect that ten years from now, maybe even five years, what he does will be considered routine.

In Dr. Bahn's examination room, I laid on my side and barely felt the insertion of the probe into my rectal cavity I watched on the screen as the data was gathered. Afterward, Dr. Bahn called me into his office and went over the results. He applies ten criteria to determine if a patient is an ideal candidate for AS [*see sidebar*]. For example, PSA is one, and only if your PSA is under ten would he consider you as a candidate.

I was an ideal candidate. I kind of knew that already, but there nevertheless was a tremendous sense of relief deeper than I had felt form my MRSI results. I was given a picture of my prostate showing me where the tumor was. I mentioned to Dr. Bahn the *(Continued on Page 18)*

study indicating equivalent mortality if treated or untreated, and he responded, with some disappointment in his voice, that we have known this for ten years. I couldn't help but think how many men had been over-treated in that time. I don't really find fault as there is tremendous pressure from patients, and a litigious system to follow established protocols. Change is slow, however the call to change is clear now, and to not heed that call would be unfortunate. I left Dr. Bahn's office elated and with a different level of confidence than I had experienced in the past four years.

Often over the past four years I have felt some minor pain in the pelvic area. My mind races with the thoughts, "is it possible that the PC has metastasized?" Hopefully, no more will that issue come up for me. The sad part of this story is that for men interested in AS there is often little support for that journey. Few doctors are comfortable recommending it. My Us TOO prostate cancer support group is not able yet to offer support to AS candidates. I recently facilitated a session at the 2009 PCRI conference and one fellow volunteered impatiently that he didn't get the support from Us TOO meetings he needed as he was the only one on AS. So major hurdles still exist for the man choosing AS, and these need to be squarely addressed by the medical community.

A note too for those considering AS vs. intervention… One issue that might figure into that decision is anxiety. Will you be less anxious if you have had intervention? Studies indicate that men who have had intervention have the same anxiety as those who don't.[2] At a meeting of Us TOO, a fellow who had undergone intervention said that he was sweating every time he had a PSA test. Interestingly, I now have no real anxiety about the results of PSA tests. I just assume they will be fine. I know folks who have had radical prostatectomies or other interventions who experience much more anxiety about their PSA results than I do. Cancer recurs in a fairly high percentage of treated patients, so once you have had treatment, the monitoring process continues. In fact, we are all on AS whether we have had treatment or not. Maybe we should just adopt terms like pre-treatment and post-treatment AS?

> ***"PSA often means Prostate Specific Anxiety"***

However, as with all things there is room for improvement. For example, Dr. Bahn pointed out to me the calcium deposits which the CDU showed as white spots. According to Dr. Bahn, inflammation may cause calcium deposits, and may be a predisposing factor to the development of PC. After four years of research in the PC area, witnessing the shifting sands, I realize that when the data is not clear one must have the courage to rely on his instincts after thorough research. At times it seems the more I read, the less I know. I have found as a result of my experience with AS that my intuition is not a bad doctor.

Maybe the best news of all of this is that I created a small cyber support group with six core AS members. Of those six, three no longer have detectable cancer. One used mother's milk, another Poly MVA. Each man forged his own path despite a powerful institutional bias towards intervention. The remaining three of us are thriving, but still have cancer which is contained. This little contingent that I call "Patient Pioneers" have provided much support in the AS journey.

Doctors remember, first do no harm. That means do no psychological harm as well as physical harm. Patients, remember, first do no harm to yourself. AS is no longer experimental. Active Surveillance is a legitimate approach, yet we still see TV programs like Larry King's recent (August 2009) program dedicated to prostate cancer where AS was barely mentioned.

No one is holding a gun to your head to have intervention. We don't need to have a pill whenever we see the Doctor, and we may not need radical intervention either. AS may not be for you, but for many men it needs to be considered as a legitimate alternative right alongside all of the others. Progressive organizations like PCRI and the Prostate Institute of America can provide guidance through these decisions. We are likely on the brink of a seismic shift in the way we diagnose and treat PC. Stay tuned. It should be an interesting and rewarding ride.

Resources

1. [Stamey TA, Caldwell M, McNeal JE, et al. The prostate specific antigen era in the United States is over for prostate cancer: what happened in the last 20 years? J Urol. 2004 Oct;172(4 Pt 1):1297-301.
2. van den Bergh RC, Essink-Bot ML, Roobol MJ, et al. Anxiety and distress during active surveillance for early prostate cancer. Cancer. 2009 Sep 1;115(17):3868-78.