

nually in erectile dysfunction that occurs from other health conditions as men get older.

Cyberknife Compared to Other Types of SBRT

The prostate gland can move unpredictably throughout the course of treatment, making the ability to track, detect, and correct for motion during treatment critically important. In fact, the prostate has been documented to move as much as 5 millimeters in less than 30 seconds because of normal patient bodily functions such as filling of the bladder, gas in the bowel, or even slight patient movement during the procedure.

Unlike any other radiation treatment, the CyberKnife system continually tracks and automatically corrects the radiation beam to adjust for movement of the prostate in real-time throughout the entire treatment session. This capability enhances the doctor's ability to accurately deliver high doses of radiation to the intended target while still preserving the surrounding healthy tissue to minimize potential side effects.

Paying for SBRT

SBRT for low and intermediate-risk prostate cancer is covered by Medicare in all 50 states and the District of Columbia. In addition, most private insurance payers

and health exchange insurers cover SBRT treatment for prostate cancer. It is always best to check your insurance policy, and if applicable, be sure to review your employee contract to determine if your insurance coverage benefits are limited.

For more information on SBRT, check with a radiation oncologist. For contact information for centers specifically offering the CyberKnife System for prostate cancer, visit <http://www.cyberknife.com/>

helpline corner: My Story So Far

By Jonathan Levy, PCRI Educational Facilitator

In February 2006, with a PSA of 4.0 ng/mL, my urologist decided that I should have a prostate biopsy. The result? The pathologist found no cancer. Since the biopsy results were benign, the doctor reassured me that I was "just one of those men, whose PSA of 4.0 ng/mL, was normal." Because of this, I wasn't re-tested for the next three years.

In 2009, during a routine physical, and because it was now long overdue, I decided that it was time to take a PSA again. It came back at a whopping 32 ng/mL. Of course, this triggered a repeat biopsy, and this time I was diagnosed with prostate cancer. My Gleason score

was 3+4=7; stage T2b. A CAT and bone scan were ordered to rule out any metastatic disease.

My wife, Doris, and I went to a meeting with the urologist to review the results, and to discuss my treatment options. When we arrived at his office, his demeanor made it clear to both of us that things weren't going to go as planned. The CT scan showed that, "the cancer had already metastasized to your liver," he said. He explained that the only treatment available now was hormone therapy, using a drug called Lupron, and that it would only be palliative, since a cure was now impossible.



My wife and I left the meeting in total disbelief and shock. We felt helpless, confused, and numb. "How do we break this news to our children?", we asked ourselves; our lives had been shattered. The next several days were an emotional roller coaster, filled with ups and downs, sleepless nights, and confusion. But, what eventually came out of the chaos was a slowly but surely formed conviction that there was something fundamentally wrong with this whole sequence of events; it didn't add up.

I started researching on the internet and found that a liver biopsy could be done, to confirm whether the doctor's

ProstateHelpline



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diagnosis of liver metastases was correct, or not. So, I requested that one be done immediately. The radiologist felt that the location would be too dangerous to biopsy, so another CAT scan was ordered instead. The results showed that what had been assumed to be cancerous liver lesions by my urologist, were actually benign hemangiomas.

To top it all off, the urologist reacted to the news as if nothing out of the ordinary had happened, and without skipping a beat, brought up the option of radiation therapy. Later, when I finally did get to see the original CT report, I was stunned. In it, the radiologist had clearly suggested to the urologist that a repeat scan be done with a hemangioma protocol.

I know that this is an extreme example, and I realize, that in his own way, he was probably only doing what he thought was best for me, but put yourself in my place. If this had just happened to you, would you continue treatment with this doctor?

What would you call this? Misdiagnosis? Diagnosis error? What I do know now, is that liver metastases, being so dangerous, are less likely to respond to hormone treatment. So, "why", I ask myself, "did he offer me this treatment option?"

This whole sequence of events drove the point home to me, and made it clear what needed to be done. No, I did not hire a lawyer. I had just turned a corner, and, I now had to become my own healthcare advocate.

So, I found another doctor. This time I asked the questions and offered the input that would help achieve what I wanted to accomplish in my own treatment. These were the questions that are repeated many times over with the men and women I speak with on the PCRI Helpline: Is my diagnosis correct? Should the pathology be reviewed? Are there tests that need to be done to provide additional details, including newer tests for genetic markers?

In my case, I chose radiation treatments along with adjuvant hormone therapy. My PSA responded so well that it reached a nadir of 0.1 ng/mL. For the next couple of years, it remained stable.

But, in 2013 my PSA started to rise, slowly at first, incrementally, and then, much more significantly. When it hit 10 ng/mL, and after doing a lot of research, I decided that I would try to find the source of the recurrence.

My journey now took my wife and I all over the country. First, we tried an MRI-fusion targeted biopsy. It came back

negative. Next, we traveled to Minnesota for a C-11 Choline PET scan. Negative. I underwent the misery of a thirty-core transperineal mapping biopsy. Also, negative. And, finally, I had an F-18 Sodium Fluoride PET scan. It, too, came back negative. Like so many men with recurrence, I just wanted to know where it was.

In April 2014, and with a PSA that had risen to 34 ng/mL, I requested that we retest with an F-18 Sodium Fluoride PET bone scan. Previously, my PSA was 10 ng/mL, and in my case, too low for even the highly sensitive F-18. But this time around, the scan clearly detected bone metastases in brilliant illumination. It was quite a light show. The upside of this new diagnosis was that I was now able to qualify for a clinical trial that I had long been hoping to enroll in.

In July 2014, I started on the SWOG 1216 Trial, a trial using the experimental drug *TAK-700*, with Lupron, in men with newly diagnosed metastatic disease, who are hormone sensitive. I believe that participating in a trial brings with it two definite benefits: one, you get to try an experimental drug, not otherwise available, that may offer as of yet unknown clinical benefits. Two, you are loaning the prostate cancer community your body and its disease in the hopes that others will derive a future benefit.