

MY PROSTATE CANCER JOURNEY

A JOURNEY WITH A “SURPRISE DISCOVERY” THANKS TO FRIENDS

I've always felt healthy. I play tennis at least three times a week and I am not too much overweight. I never get up at night to use the toilet. I am 72 and cancer does not run in the family. So here is what happened? As many men get prostate cancer I hope many will find this useful. Feel free to pass this on to friends.

PHYSICAL & HIGH PSA: Dr. Robert Phillips, 972-566-7976 at Medical City Hospital, Dallas 6/21/07: Every year I get a **physical** from the same doctor. Each year Dr. Phillips does the finger prostate exam and this year he said he might have felt a change in my prostate. In 1996 my PSA was 0.9. Over the years it has gone up and down but was never very high. In 2006 it was 3.3. In 2007 a jump occurred to a **PSA of 6.2**. Although many have PSA's over 6.2 the **rapid increase is the concern**. I was most impressed with Dr. Phillips finger's sensitivity as the 6.2 reading came in several days after the physical and the doctors below seemed to *feel* no problem. Dr. Phillips called me on 6/25 and sent me to Dr. Gruber, an Urologist at Medical City, for a biopsy.

BIOPSY, CANCER & NERVE SPARING OPEN SURGERY: Dr. Michael Gruber, Urology & Urologic Surgery, 972-566-7771 at Medical City, Dallas 7/25/07 (www.uant.com) Urology Associates of North Texas: I was most impressed with Dr. Gruber. The **biopsy** was totally painless. Twelve biopsies were taken. The results came back a few days later and Dr. Gruber called me for follow-up meeting on 8/2 as cancer was found. Of the **12 biopsies 2 had cancer**. Both were located side by side and on the side of the prostate. Both had a **Gleason score of 6**. One biopsy had 5% cancer and the other 30% cancer. Dr. Gruber discussed all my options thoroughly; at least that's what I thought. **He leaned toward surgery** which seems to generally be the recommendation if one is healthy. He has a great track record and only performs **nerve sparing open surgery**. Note: Nerve sparing is code for trying to retain your sexuality. He recommended other doctors in his group for the other procedures (Seeds: Louis Munoz 972-566-7081 & Robotic Surgery: Keith Waguespack 972-401-4940). This is a very impressive group of doctors. My biopsy evaluation was handled by US Labs in Florida 352-787-7650.

FRIENDS: As I now have cancer, I sent a letter to many friends and began talking to people who have had similar problems and many have. Many have had success. Several have had problems with urinary accidents (a few very serious and on going) and several have lost their ability to have sex. Many recommended doctors. The Internet also provides a great deal of information. Books some recommended: “Prostate Cancer A to Z” by Pienta & Moyad & Dr. Patrick Walsh's “Guide to Surviving Prostate Cancer”. I should note that these books do not tell you about what I ultimately choose. A great reason to share with others is that it is amazing how helpful friends can be. **Sharing with other is very important.** *We are better than me.*

LIPOSCOPIC NERVE SPARING SURGERY: Dr. Jeffrey Cadeddu, Associate Professor Department of Urology, 214-645-8765 at Southwestern Medical Center Dallas 8/20/07 (Brent Kirkley's doctor): Jeffery Cadeddu seemed extremely knowledgeable and talked Jan & I through all the alternatives (except one). His office was by far the best run and friendly. He was on time and gave us what ever time we wanted. He does **nerve sparing open surgery** and **liposcopic surgery** and **leaned toward liposcopic** as it is less painful and you heal faster. He stressed that I'd be “just fine”, my cancer is in a very early stage and actually he had me thinking that simply **watchful waiting** was a possible alternative. **Watchful waiting is checking your PSA two to four times a year and a biopsy every year or so.** The issue here in not having cancer get out of the prostate but the longer one waits the less likely one recovers their urinary and sexual ability (if at all) due to aging. Nerve sparing is key (sex issue), so finding a “very” experienced doctor like Dr. Cadeddu is critical and even then one can still have a problem. The sex nerves are the size of hair and they run right next to the prostate. I'm sure if I choose this procedure Jeffrey would be my choice.

SEEDS OR EXTERNAL BEAM RADIATION: Dr Barry Wilcox, Radiation Oncologist, 214-370-1400 at Baylor Medical Center, Dallas 8/21/07 (Dr Wendell Jones's doctor): Although Barry Wilcox office was not as well run and had a bit of an uncomfortable feel he was impressive. The uncomfortable feel came from a hospital odor and an old patient in the waiting room with a black and almost missing nose from radiation. I guess radiation does that. Two close friends of mine had **external x-ray radiation** which cost them their sex life and they have urinary problems as well. One said it was a very depressing process as he waited with the same people every day, many are in bad shape and several died. I definitely do not want external x-ray radiation. Dr. Wilcox said he performed 500 **seed implants** and virtually no one has urinary problems so seeds definitely are better than x-ray radiation. Dr. Wilcox scheduled me for an **MRI 8/24** to make sure cancer had not spread outside the prostate. When I told Dr. Wilcox I was attracted to watchful waiting his reaction was “you've got to be kidding” which scared me a bit. **The MRI results showed that cancer does not exist outside the prostate. Also Baylor looked at my previous biopsies and confirmed the results.**

SEMINAR ON SEXUAL AND URINARY PROBLEMS: Dr. Gruber is a member of a large association of doctors. I received an invitation to a seminar on these problems that took place in Arlington, TX. I arrived a few minutes before it began and was shocked to see perhaps 500 people there. All previous doctors mentioned sexual and urinary problems were potential

problems but the meeting's huge attendance confirmed that these are major problems. I have seen figures like other types of radiation or surgery can cause sexual problems in 40-60% of men and urinary problems in 30-50%. The meeting started with two doctors who specialized in each of the problems introducing a 60 year old retired veterinarian who had open prostate surgery resulting in sexual and urinary problems leading to depression. I won't go into detail, but the patient had an implant inserted in his body solving each problem. Go to <http://www.americanmedicalsyste.ms.com> for more information. The doctors were V. Gary Price and J. Daniel Johnson 972-401-4940. I'll add that a friend had the urinary implant installed and had complications. During the question and answer session a couple people asked about proton radiation therapy, but the subject was basically side-stepped.

PROTON RADIATION: Proton Radiation Center at M. D. Anderson Hospital (1840 Old Spanish Trail - Houston): I discovered this procedure thanks to a friend, but not until after I saw the above doctors. Hank Lauten gave me an article and suggested I check it out. It is said to have by far less side effects. There are only a few Proton Radiation Centers in the country (none in Dallas). The downside is that it takes about 38 treatments (similar to x-ray radiation); one per day Monday through Friday for 8 weeks and one must go to M. D. Anderson in Houston. See: http://www.mdanderson.org/care_centers/radiationonco/ptc/ & <http://www.protonbob.com> & <http://protonpals.net/> The M. D. Anderson website is fantastic. A new \$125 million dollar building was built just for this procedure. The first treatment here was May 2006. In the past 1 1/2 years 220 people have been treated (patients will exceed 2000 by 2011). Contacts: Initial contact Veronica Ramsay, RN (713)563-9397, Urology Department (713)792-3100 Dr. Andrew Lee, Tia Ly (713)563-9398. My first consultation at M. D. Anderson was 11/15/07. Treatment will follow at a future date if I am accepted.

SOUND: Sonablate 500 Acoustic Ablation in Toronto: Process not approved in the USA yet but showing good results thus far and virtually no side effects. Go to: http://www.bestlifeonline.com/cms/publish/health-fitness/Sounding_Out_Prostate_Cancer2.shtml
Cost about \$20,000 and not covered by insurance.

SUMMARY: The bottom line is there are numerous choices. Watchful waiting, hormonal, cryosurgery (freezing), IMRT external x-ray radiation, seed radiation, "nerve sparing" open surgery and "nerve sparing" liposcopic surgery (sometimes done with a robot – suggest you read ED General Discussion on protonpals.net about "nerve sparing" which may or may not be nerve sparing) & proton radiation therapy. Cryosurgery is out as it for sure eliminates your sex life. External x-ray radiation is also eliminated due to my friend's story (actually several friends' stories). I didn't consider Hormonal, but I know this is often given along with other treatments. I should note that at least two friends stressed you must have surgery and get the cancer out of your body, but I'm not so sure due to the concern of side effects although liposcopic nerve sparing surgery would be my second choice.

My conclusion in order of preference are:

Proton Radiation Therapy: at M. D. Anderson in Houston

Once I knew all the facts the decision is a no-brainer.

Upside: No pain at all and effective. Fewest side effects the worst of which is possible fatigue. Unlike very common x-ray radiation it only affects the cancerous area not all the nearby body tissues. People who live in Houston have the daily treatment and go back to work the same day everyday. After a week of treatment, I get in my car and drive to Dallas with no problems.

MD Anderson is the only facility in the Southwest but facilities are being built in the USA.

Downside: Possible fatigue and 8 weeks in Houston. The hospital provides a list of places to stay like. Note: Although surgery is accomplished in a day the healing takes at least as long as this prolonged process.

Special Note: After starting treatment I discovered that over 1/3rd of the patients are given hormonal therapy shots of Lupron. This has significant side-effects and could influence one's decision. I believe shots are required if cancer is more advanced or the prostate is greatly enlarged. This treatment eliminates sex drive, causes hot flashes, possible bone pain, etc. for at least a six month period.

Laparoscopic surgery (prostatectomy/removal of prostate) by Dr. Jeffrey Cadeddu

Upside: Likely to totally eliminate cancer

Downside: perhaps urinary problems (incontinence) & perhaps loss of sex life.

Radiation seeds (Brachytherapy) by Dr. Barry Wilcox

Upside: Less likely side effects than surgery & less painful operation. Probably no urinary problems.

Downside: perhaps loss of sex life. If it doesn't work surgery is not an option later. A friend of mine had a serious problem with his bladder years after this treatment called "radiation cystitis" which is serious.

Watchful waiting or active surveillance (perhaps trying some of the food and herb things to help still more). The 5-year survival rate for men with early-stage prostate cancer is nearly 100 percent. The 10-year survival rate is 86 percent and the 15-year survival rate is 56 percent. The average age of men at diagnosis is 65 years old.

Upside: live a normal life (perhaps) & you can have radiation or surgery later.

Downside: perhaps cancer spreads, surgery is less successful the older one gets.

Note: The goal is to eliminate cancer and save your sexuality and not have urinary problems. All of the above doctors were very impressive and all spent time describing my possible choices, however no Dallas doctor mentioned Proton Radiation.

PROTON RADIATION

History of proton therapy in the United States

This is not an experimental process. The first suggestion that energetic protons could be an effective treatment method was made by Robert R. Wilson in a paper published in 1946 while he was involved in the design of the Harvard Cyclotron Laboratory. The first treatments were performed at Particle accelerators built for physics research, notably Berkeley Radiation Laboratory in 1954 and at Uppsala in Sweden in 1957. In 1961, collaboration began between HCL and the Massachusetts General Hospital to pursue proton therapy. Over the next 41 years this program refined and expanded these techniques while treating 9,116 patients before the Cyclotron was shut down in 2002. Following this pioneering work, the first hospital based proton treatment center in the United States was built in 1990 at Loma Linda University Medical Center in Loma Linda, California (recently renamed the James M. Slater Proton Therapy Center). As of early 2009 Loma Linda has treated over 13,000 patients. Loma Linda was followed by The Northeast Proton Therapy Center at Massachusetts General Hospital (recently renamed the Francis H. Burr Proton Therapy Center), to which the HCL treatment program was transferred in 2001-2002. Proton therapy for ocular tumors is also available in Sacramento at the UC Davis Proton Facility, a facility operated exclusively by the UC San Francisco Department of Radiation Oncology. It is estimated that over 44,000 patients have been effectively treated with proton therapy. Now on line as well is the Midwest Proton Radiotherapy Institute at Indiana University. In the summer of 2006 treatment started at two new facilities: the for-profit University of Texas M. D. Anderson Cancer Center in Houston, Texas, and the University of Florida Proton Therapy Institute in Jacksonville, Fla. The University of Pennsylvania is slated to open the biggest proton therapy institute in the world in 2009. In July 2007, Central DuPage Hospital in Winfield, Ill. contracted to bring proton radiation to Illinois. Patient treatment is expected to begin by 2010. Note: I'm not an expert here but I believe M. D. Anderson and perhaps Loma Linda are the only two centers that are specialists for prostate cancer and if you have to travel and stay somewhere for treatment I'd go to Houston as it has a new \$125 million state-of-the art facility devoted to proton therapy and is world famous for cancer.

(1) INITIAL VISIT: Proton Radiation Center at M. D. Anderson, Houston, Texas – exploratory visit 11/15/2007

What a totally amazing day! I drove to Houston 11/14 and found the Radiation Center easy to find. I arrived near sunset and the new building looked beautiful. It is just over a year old. On the morning of the 15th I arrived 30 minutes early. No problem and no wait. I can't remember not waiting at a medical facility and have never been received early. The young woman (Heather) near the entry behind the modern desk (not a little sliding glass window) greeted me with a big smile and had my paperwork already mostly filled out. The next gal (Evette), sort of a business person, had another big smile and assured me this was the greatest place in the world and that everyone loved it. She quickly dealt with a pile of paperwork that most hospitals would spend an hour on. She said "everyday is a party". I wasn't sure what that meant. We got in an elevator and went down a floor to a fancy waiting area. Sure enough it looked like a party. There was a spread of food and a bunch of very friendly happy folks, a mixture of mostly patients, patient's families and some employees. I started wondering where all these folks come from as I've never seem so many clearly happy folk in one place. Remember this is a cancer center – so it's most amazing! Then my personal nurse (Evangeline) appeared and she was equally friendly and made you feel welcome and comfortable. Again paperwork but quickly handled and an explanation of what it was all about. Next my Nurse Practitioner and main contact arrived (Tai). I've talked to her several times on the phone and most calls were initiated by her. The folks here seem to always take the initiative. How many times have you had a doctor or nurse call you?? (A few weeks later Tai was writing e-mails to Jan during Jan's surgery). Then another pleasant nurse (Michelle) took blood. No pain and more smiles. Next someone (Sloane) came in to see if I needed help with housing or anything else. Finally my doctor (Andrew Lee) appeared. He was young and very sharp. He didn't push Proton Therapy but said over 200 patients thought it, the process was wonderful and side effects seemed minimal. He seemed to lean a bit toward my just doing Watchful Waiting so he really wasn't selling anything. Dr. Lee said he accepted me as a patient but it was my decision. This was an important step as they only have roughly 30 patients at a time and there is a waiting list. They are also selective and typically will not take patients with a PSA over 20, Gleason scores over 8, people with cancer spread out of the prostate or with pacemakers or hip replacements. After Dr. Lee left I mentioned Watchful Waiting to Tai my Nurse Practitioner and she said that's too much work (regular blood test and biopsies and cancer generally grows and must be eventually dealt with) and Proton Radiation works. This made the decision for proton radiation easy. Never have I seem such a friendly helpful professional group of folks in one place. Somehow they figured out how to have everything evolve around the patient and actually transmit that feeling to the patient. I walked away with a stack of brochures, booklets, a DVD on proton therapy and other helpful things. I also ended up with 7 business cards from the doctor, nurses and other professionals all of which made it a point of saying they were there for me and to call them as they gave me their card (it wasn't something you picked out of a display as you checked out and I didn't even need to check out). Everyone, including the doctor, also gave me their e-mail address. How often have you wanted to talk to your doctor or at least his assistant and found that virtually impossible without an appointment? And yes, the place even has free parking. As I walked away I took a maple donut from the food spread, (about the only flavor donut that tempts me and a flavor I rarely see), believing that the donut must be a sign that I'm in the right place. This place is worth a visit from every doctor's office and anyone else running a business as a place to emulate. I can't wait to go back for treatment and I've never said that before but that is the environment the Center's team has created.

(2) SIMULATION DAY at M. D. Anderson 12/13/2007

Today I drove to Houston and back to Dallas spending about two hours at the Proton Therapy Center. The purpose of the simulation is to make sure the protons hit the target when therapy begins. I had numerous CT scans (sort of like a mini MRI) and ended up with big X marks on my body that will be used to line me up for treatment #1. Some good news and bad news. The good news is that everyone there is still really great and I met a few more really nice folks. The bad news is apparently every day is not a party. The party I walked into on my last visit was apparently thrown by a patient who completed treatment, but as there are many patients there will be many parties (nuts, parties just got cancelled due to health regulations).

(3) TREATMENT Began 1/2/2008

Jan and I drove to Houston January 2nd for my first treatment at 3:55pm. I had a treatment that Wednesday as well on Thursday and Friday and met for a consultation with my doctor Andrew Lee. Every week you meet for a consultation with the doctor. The bottom line is that I felt nothing and had the opportunity to talk with several patients who are almost complete with the program. None had any side effects although one said he had bouts of extreme fatigue after doing work.

I now know quite a bit more. There are 4 proton therapy machines at M. D Anderson; one is devoted solely to prostate patients. **Proton radiation is best for the prostate, lung, esophagus, liver, rectum, sarcomas GYN tumors and the brain. I'd encourage anyone with cancer to be sure to investigate proton radiation, even though it may not be on the list. The protons are made from hydrogen.**

At my simulation a computer model of my prostate was captured and six 20# brass plates were made with a hole in each just slightly larger than my prostate (three plates for each side view of my prostate). A Lucite plate is also made which is used to compensate for bone /fat density for your body so that equal treatment is done across your prostate. You lay flat on a table and beams are shot through one hip, then the other. The plates are rectangular with a hole in the center to exactly match my prostate. The plates are designed so that radiation only minimally gets to body parts other than the prostate. The proton beams are shot through the hole at the side of my body where the simulation visit X's were drawn. The X's are used only minimally during the first treatment for a preliminary starting point as the actual aiming each time uses your bone structure as viewed with an X-ray machine. It is all very precise. The radiation treatment lasts only a few minutes, but the overall hospital visit takes about an hour. This will take place Monday through Friday for 38 total visits.

Proton therapy is cancer killing machine that targets cancer with precision to a millimeter while sparing nearby healthy tissues and causing very few, if any, side effects. The common X-ray radiation you may hear about is not proton radiation. It is amazing something this terrific seems to a secret to most of the world. Most people seem to discover it by accident as was my case. It seems doctors are good at sharing all the options but leave this option out as their group cannot perform this procedure. Again this is not being done anywhere in Dallas. For the record Medicare pays for this although the patient is responsible for travel, room and board. I understand the retail price for the procedure is \$144,000. I eat no differently, play tennis, and do everything I normally do. At this time there are only 5 proton therapy centers in the USA with Loma Linda and M. D. Anderson being the most focused on prostate cancer.

I've taken pictures of almost everything and everyone that I've described above. To view the pictures go to <http://protonpals.net/> and click slide show.

On 2/22/2008 38 treatments were completed and I'm done. Haven't felt any different or had any significant side effects.

How Do I Know I'm Cured?

After my last treatment I ring a gong, have a little ceremony and go home. That's it. I believe that I am cured. The proof will come in the form of blood work. My PSA should fall. The doctor also gives a digital rectal exam DRE of my prostate. Here is my schedule:

3 months Returned to M. D. Anderson. **PSA dropped to 1.3** and doctor's digital test proved OK.

6 months Mailed in kit given me my M. D. Anderson with blood drawn in Dallas. PSA dropped to **1.2**.

9 months Return to M. D. Anderson. PSA remained at **1.2**.

11 months (happened to be in Houston – normally it would be mail in at 12 months) after completion. **PSA dropped to 0.8**

18 months Could have mailed blood but to M. D. Anderson. PSA dropped to **0.5**.

24 months Mailed in blood. PSA **0.4**.

30 months PSA **0.3**

36 months Mailed in blood. **0.4**

Typical Patient Check-up Schedule:

Year 1: Every 3 months.

Year 2, 3 &4: Every 6 months

Next 6 Years: Once per year

Note: M. D. Anderson wants to do all blood evaluation as different labs come up with different results. For example, my PSA before treatment in Dallas was 6.2 and M. D. Anderson measured a PSA of 3.9 prior to treatment. The numbers I will be tracking are PSA 3.9 (11/15/07) and testosterone 467 before treatment (normal range 241-827 11/15/07).

➤ *Note: If you want to discuss anything mentioned above, feel free to call me in Dallas at 972-233-3996. Ban Capron
Ban updated 5/1/2011*

Join ProtonPals *now* to keep up your knowledge on cure results

3 Ways to Join

**Go to protonpals.net and click “Sign-up”
Enter your name & contact information
in the ProtonPals book in the patient gown room
Call Joe Landry at 832-335-0353**