

## MY EXPERIENCES AT LOMA LINDA - by Bob Clark

December 21, 2004  
(Updated 11/02/2015)

Background: I was age 66 when diagnosed with prostate cancer. No symptoms whatsoever. Physically active, generally good health, recently married, active sex life. PSA: 10/2002 - 2.0; 8/2003 - 6.5; 4/2004 - 4.03. *Two biopsies* (12 core samples each time): 12/2003 - one precancerous area; 5/2004 - cancer in both hemispheres of the prostate, 3 of 6 quadrants, 2 to 4% of the sample tissue was cancerous. *Digital Rectal Exam:* - negative. *Gleason:* 6.0. *Stage:* T1c based on DRE, or T2a clinical based on cancer found in both hemispheres of prostate.

I heard of Loma Linda University Hospital and Proton Radiation Therapy through a tennis playing friend who referred me to his minister who had sent a number of men in his congregation to LL, and through Bill Wible of the Albuquerque Prostate Support Group who had completed treatment at LL December 2003. Bill acquainted me with the Proton Bob web site and gave me the name of Ken Paul, an Albuquerque resident and friend of 35 years who had completed his treatment at LL in 2002.

Sent LL information on my diagnosis and relevant medical history on June 10<sup>th</sup>. LL called me June 15<sup>th</sup> for insurance information. I visited LL July 15th for consultation and was accepted for treatment in October (my choice). Visited LL again September 27th to have a CAT scan and body mold made.

My experience: I underwent nine weeks of proton therapy from October 11<sup>th</sup> to December 14<sup>th</sup>. The program consisted of 44 treatments; five treatments per week, Monday through Friday. Daily preparation consists of emptying the bladder, then drinking 16 ounces of water 30 minutes prior to treatment, getting out of street clothes and into a hospital gown, going into the treatment room, laying down in the body mold, having a balloon inserted into the rectum and filled with 4 ounces of water, and having an X-ray taken to determine the exact location of the prostate on that day. Actual treatment takes about 2 minutes. Following treatment the balloon is removed, you get up and get dressed back into street clothes. Average time from in-the-door of the hospital to out-the- door was about 45 minutes. Each patient has one doctor responsible for his treatment. The patient sees his doctor once each week during the nine weeks of treatment. The water you drink expands the bladder and protects it from the radiation. The rectal balloon protects the colon from radiation and while it is uncomfortable, it is not at all painful.

Side effects: *After about 20 treatments* I noticed that it took me longer to empty my bladder, and that when I had to urinate I had some urgency and perhaps a slight burning sensation in the bladder. My doctor told me this was normal and would go away a few months after the treatments were finished (it did). The proton radiation irritates the prostate, causing it to swell and compress the urethra making urination slower. My doctor prescribed Uroxatrol which seemed to help, and said that I could stop taking that medication 2 weeks after the last treatment (I have). I found out later through another patient that taking two Ibuprofen daily also seemed to help urine flow. *After about 30 treatments* I developed pink spots on both hips where the proton beam entered my body. The doctor said these would go away a few months after treatment was completed (they did).

How radiation works: I was told that proton radiation and conventional (photon) radiation work the same way; they damage the DNA of the cells they come in contact with. Cancer cells, because they divide more frequently than normal cells, have more fragile DNA and cannot repair themselves in the time between treatments. Normal cells can and do have time to repair their DNA. When the cells reach their normal life expectancy and die, the normal cells regenerate themselves while the cancer cells die out.

Why Proton? Radiation is either diagnostic, as in the case of an Xray, or therapeutic, as in cancer treatment. Conventional (photon) radiation sends a stream of electrons all the way through the body. Electrons are light weight particles and tend to scatter when they collide with atoms in the body's cells. The doctor has to put a lot of conventional radiation into the patients body in order to get the required dose of therapeutic radiation into the tumor. Photon radiation causes damage to the tissue along it's entire path as it passes through the body. Radiologists try to minimize this damage by using different entry points and allow the individual beams to converge in the area of the tumor. Protons are heavier than electrons and less susceptible to scatter when they hit other atoms in the body's cells. They also have a unique characteristic that they can be stopped at the tumor and deposit most of their energy in the tumor. LL claims that proton radiation can be stopped within 1 millimeter of the intended target. In my case radiation was applied through my right hip one day and through my left hip the next, alternating back and forth with each treatment.

Why LL? Until recently LL was the only location in the United States that offered proton radiation. They built their facility in 1990 with the technical help of Los Alamos National Laboratory. The proton accelerator and four treatment rooms were a \$100 million investment. Harvard Medical School (Massachusetts General Hospital) brought a facility on line in 2002 and the University of Indiana proton facility began treatment in 2004. MD Anderson in Houston is breaking ground in 2005 for their facility. LL has the capability of treating 160 patients a day. The treatment rooms run from 6 a.m. to 10 p.m. Monday through Friday and are used to treat tumors of the prostate, brain, eye, spine, lung, and other organs, as well as macular degeneration. LL is under contract to the Department of Defense to determine if proton radiation can be used to treat breast cancer. Five year cancer free survival rates after proton treatment is equal to or better than other therapies (surgery, photon radiation, etc.) but proton treatment produces fewer side effects.

Insurance: There was no cost to me other than living expenses. Medicare and my secondary insurance paid for all medical treatment.

Support: Tremendous! LL sends new patients a packet that includes information on housing options in the immediate area for all budgets. Patient pot luck dinners Monday and Tuesday nights each week at two different apartment complexes are open to all proton patients and spouses, regardless of where they live. Support group meeting at the hospital Wednesday night are open to all with guest speakers and lots of jokes from the MC. There is a weekly wife's support group/luncheon for ladies only. There is a dinner at the restaurant-of- the-week on Thursday nights. Patients and spouses have the use of the full university athletic center facilities and library available to them at no charge. There are lots of golf courses and other attractions in the area. My nine weeks at LL passed very quickly and my wife and I made many new friends.

Contact: LL Proton Referral Office 800-496-4966 or 909-558-4288. Good information is available on the Internet at [www.llu.edu/proton/](http://www.llu.edu/proton/) and at [www.protonbob.com](http://www.protonbob.com).

Update 11/02/2015: PSA 0.17 ng/ml