

March 31, 2011. Houston, Texas

Introductory Note: Over 30% of the men at the Proton Center are given hormone shots of Lupron for six months, while another 20% are on Lupron for 24 months.

Joe Landry: Lupron Legionnaire Dave was first diagnosed with prostate cancer in 2005 by his urologist, with a single positive sample of a Gleason 6 (3+3) and 19 negative samples out of 20 tested. He chose “watchful waiting”, with an emphasis on the waiting part, he says. Dave began leuprolide (Lupron) therapy on August 5, 2010, and it runs until August 2012. He successfully underwent proton therapy at the Proton Center from November 10, 2010 to January 6, 2011. He is here to tell us about his experience with Lupron.

Before we begin, can you describe briefly what Lupron does in treating prostate cancer?

Prostate cancer cells are stimulated by testosterone. They need it to grow. Without it, they die. Lupron’s job is to starve those cells to death by shutting down testosterone production. That’s it in a nutshell.

OK, but doesn't proton therapy kill all the prostate cancer cells anyway?

Not necessarily. Cancer cells (either singly or in tiny groups) are found throughout the body. A tumor in your prostate may be the source of microscopic groupings of prostate cancer cells hidden elsewhere in the body, undetected by an MRI or bone scan. Sure, the proton beams can destroy the tumors and cancer cells located in the prostate itself, but the beams have no impact on any single or small groups of prostate cancer cells located outside the prostate. These outlier cells remain as a possible future source of a relapse or of cancer elsewhere in the body. The Lupron kills these outlier cells, but that process can take time. For patients with bulky local disease, medications like Lupron can also improve cancer control rates.

What was your PSA and Gleason score?

My first day at MD Anderson, my PSA was a 4.4, but because I was on finasteride when I arrived at the Proton Center, you have to double the score. So, in effect, my PSA was the equivalent of a 9. Worse than that, one of my tissue samples was what I call a bad Gleason 9 (4+5) and the other was a Gleason 7 (4+3). The Gleason 9 put me in the “high risk” category of prostate cancer patients.

Do you think leuprolide helps you?

I think leuprolide helps me personally in at least two ways. First, because of what it does, the Lupron provides the benefit to me of potentially living longer. Now, I like that! Second, having Lupron therapy now may avoid a significant risk to me of needing a lot of it later on, in the event of a subsequent failure. I figure it’s better to be on it for 24 months now, instead of risking having to be on it for 3 or 5 or 10 years later on.

When did you start at the Proton Center?

I was accepted for proton treatments last August, but my doctor, Dr. Lee scheduled the start of my treatments in November to allow the hormone therapy to work on the prostate cancer cells. He put me on bicalutamide (Casodex) for the first 30 days and started me on Lupron. Back then, Dr. Lee told me that I would be on Lupron for a total of 24 months, with shots given every four months, but that the proton therapy would start after 2-3 months.

Do you know yet how the Lupron has worked out for you?

By late October, Lupron had lowered my testosterone to less than 20 from the mid 400’s, which meant prostate cancer cells were dying. That was reflected in my PSA, which dropped from about 9 way down to 0.3. The Lupron shrunk my prostate, too. All this happened before the first proton treatment. In the blood test I took this week, which is three months after completing proton therapy, my PSA is now less than 0.1, and my testosterone remains at less than 20.

Men talk about side effects from Lupron. Can you tell me what yours were?

The usual ones most of the time --- zero sex drive, hot flashes, occasional pain in my joints, etc. I didn't gain much weight, only about 5 or 6 pounds, primarily because I continued lifting weights and doing aerobics on my stationary bicycle while on Lupron. Believe it or not, after 8 months on Lupron, my bald spot at the crown of my head is now covered over with hair. So that's a plus. Compared to leuprolide's benefits, these side effects are a small price to pay, in my opinion.

What was it like for you when you finished up your proton treatments?

I figured that once I rang the gong on January 6th, and the proton therapy was done, my life would return to normal. But I had another 19 months to go on Lupron --- 19 months as a Lupron Legionnaire. When you do the math, that's nearly 80% of my combined Lupron-Proton treatment program left. Physically, I felt great, and what joint pain I had went away after I resumed a vigorous (for me) program of weight lifting and aerobics, as ordered by my doctor.

Soon, however, I started to miss the activities at the Proton Center. Really, I did. Despite the balloons. Two weeks after I gonged out, my wife and I had dinner with another Lupron Legionnaire and his wife, and he said he missed the Proton Center, too. What was happening here? I mean, the PTC (and MDA) is a HOSPITAL, folks. I think we both missed our locker room support group. Along with that, we both missed the sense of mission you get when you're coming in each day to hammer the cancer in your prostate.

It's been nearly 3 months since you finished the proton treatments. Are you taking anything now, in addition to Lupron (other than Flomax, cranberry pills, etc.)? About two weeks ago, Dr. Lee prescribed an anti-depressant for me to take, to deal with some slight depression that I had recently been experiencing. It went away overnight and I've been fine since.

Do you feel like discussing what that was all about?

Sure. Going into mid-February, everything was fine physically. My work outs were great, and I put in full days at work. I was healthy, and beginning to lose weight. But I started having brief periods (maybe an hour or two at a time) where a very mild depression set in, where I didn't feel like doing a lot. Then they got longer. One afternoon toward the end February, I started my own little pity party, with me as the guest of honor. After about maybe an hour, I thought to myself, You're a Sunday School teacher at your church, you have this great Bible verse at the top of your plaque --- you tell other people they should read their Bible, but you don't follow your own advice! I then opened my Bible to Romans 8:28 (the verse on my plaque) and read and re-read that one and Philippians 4:4-7. It didn't take long after that for most of the fog to lift.

Now I wanted to get rid of the rest of the fog. That's when I sent my email to you, Joe, at the Proton Pals Website asking how other Proton Center Lupron Legionnaires on 24 month stints solved the problem. I learned that there was little information on this, partly because the 24 month Lupron regimen has been around for only the last year and a half.

That's when I started to read more about leuprolide as a means to help both myself and hopefully share my experiences with other Proton Pals who are interested. You told me about the YANA website, and some others. A week later, a few of us from the Houston area had a mini-reunion dinner. Getting back with our support group really lifted my spirits. One of the guys at the dinner told me that he never got even mild depression because he was continuing with his pre-existing Prozac while on Lupron. Soon after, I contacted Dr. Lee and started taking the medication he prescribed, and the problem disappeared almost at once.

You said something earlier about losing weight.

I weighed 200 lbs the day I rang the gong. I was 189.5 with 17.5% body fat the other day. So I've lost just over ten pounds while on Lupron. It can be done.

What is the secret of your success?

I exercise 6 days a week, and stay off or go real easy on the booze and the sweets. I eat breakfast like a king, lunch like a prince, and dinner like a peasant. Having soup for dinner with canned chicken or tuna added, with some veggies and maybe a little fruit, nothing else. An exercise regimen that combines some cardio and some strength exercises has been shown in clinical studies to help men who are taking hormone therapy. I think it has helped me a great deal.

What are some "take-aways" you can give us from your experience so far on Lupron?

1. Because Lupron is a "no-brainer" for me, my focus is on strategies for dealing with its side-effects. I think there are basically two kinds: One is adjusting your attitude (like the ones I've been talking about) and the other is to get medication if you need it. I have benefited from both types.
2. We have the finest doctors anywhere here at MDACC's Proton Center. **CONTACT YOUR DOCTOR WHEN YOU HAVE A PROBLEM.** Your doctor is a phone call or email away. Our doctors respond quickly. They care and they are eager to help.
3. My fellow alums from the PTC are a terrific resource and support group. I'm looking forward to a reunion with them here in Houston next week.
4. The Proton Pals are also a great support group. We're starting up a new Lupron Legionnaires discussion board on the Proton Pals website, so that all of us can share our personal experiences and learn from each other. Access to the discussion group

Please send us your input by contacting Dave at LupronLegionnaireDave10@gmail.com or if you receive this by e-mail simply click reply to Joe Landry. We are looking for comments on how you function either during treatment or well after. You can provide "your first name, e-mail address (optional) and completion date" or say "anonymous and completion date". Also indicate if you had proton radiation only (P) or proton and hormonal therapy (PH). Always put your completion date. Please be brief.

Join ProtonPals and the Legionnaires Discussion Group "now" and keep up your knowledge on cure results 3 ways to join

1. Go to Sign Up at protonpals.net and click "Sign Up"
2. Enter your name and contact information in the ProtonPals book in the patient gown room
3. Call Joe Landry 832-335-0353

Join the PALS DISCUSSION GROUP "now"

1. Go to [PALS DISCUSSION](#) and register.
2. Enter a User Name and Email address
3. Use the password sent to you in return email.