

Low Dose Thalidomide (and more regarding Leukine and Revlimid)

If you are considering treatment with Thalidomide during an off-phase from androgen deprivation therapy (ADT) to extend that off-phase when PSA levels are rising, the email below from a fellow prostate cancer advocate, Jim Waldenfels, provides his experience with this medication accompanied by Vitamin B6. Jim has done extensive research into medications used in his own treatment, and he and I have attended several conferences on prostate cancer, participated as Consumer Reviewers in the Congressionally Directed Medical Research Program (CDMRP) Prostate Cancer Research Program (PCRP), as well as the 2007 Innovative Minds in Prostate Cancer Today (IMPACT) gathering of over 100 prostate cancer survivors/advocates along with 600 physicians and research scientists. Obviously, he can be considered a very reliable source of information.

"Dr. Leibowitz and his former partner Dr. Tucker had a letter to the editor of the journal Oncology, September 2002, that described their approach and results in a fairly small number of men. I'm sure he has also posted about it at his website. **(MY NOTE: Read a lengthy discourse on Leukine, Revlimid, and Thalidomide by Dr. Liebowitz at:**

http://www.compassionateoncology.org/pdfs/Leukine_and_Revlimid-020408.pdf

or if the foregoing will not open, try:

<http://tinyurl.com/4ghuhx>)

He also mentioned it in the recording of his talk to the National Conference on Prostate Cancer 2003 in Burbank, California, minutes 37-38. Basically, it involves 50 mg daily of Thalomid plus 300 mg daily of vitamin B6 to help prevent peripheral neuropathy, one of the risks with Thalomid. He says that they see an 80 to 90% drop in PSA in the first two to four weeks on the drug. I wish! For my challenging case, with an intact prostate that was originally packed with cancer - all biopsy cores positive, most 100%, I don't get that kind of drop. Since I have an intact prostate, which more or less recovers during the off-therapy phase, I don't resume treatment at a low PSA level. My target to resume was 10 the first time I did this, and I thought it would be in the 6 to 7 range this second time. It's a longer story, but I'm now thinking again that 10 would be wise.

The first time, after 28 months off therapy (31 months on, starting December 1999), I got a six month extension of the holiday using Thalomid. This second time my oncologist and I thought it best that I go off therapy as soon as I got my PSA below .05. I succeeded in December 2006, after 19 months. I did well off-therapy for 14 months until February 2008, but my PSA had risen to 6.95 in late January. Starting Thalomid on February 6, my PSA dropped to 6.08 on March 6 (the low-point on thalomid this cycle). It bounced around a little in April in the 7 range, partly due to different PSA tests, but the last value was 6.46 on May 21, and I'm happy with that. As you see, I've extended my off-therapy period to 18 months and counting.

You probably would get considerably better results.

My quality of life is very good. There are side effects of Thalomid, which can be countered to some extent. Drs. Leibowitz and Tucker feel that the most serious side effect - peripheral neuropathy - can be prevented by using the low dose of 50 mg coupled with the 300 mg of vitamin B6 daily. They tried different dosing combinations before finding this one that seems to solve the problem. I've experienced no peripheral neuropathy. Thalomid was originally marketed as a sleeping pill (before those horrendous birth defects were noticed), and it certainly gives you a sound sleep. However, it is known for a degree of morning sluggishness. For me that is not pronounced, but it is noticeable, and even coffee does not fully counteract it. Constipation is another possible side effect, but I'm convinced that can be fully counteracted. I exercise regularly, eat a high fiber diet, and get plenty of water, and constipation is not a problem at all. By the way, those are some of the tactics recommended by a site addressing countermeasures for thalidomide side effects that is probably still available under the Cleveland Clinics advice for multiple myeloma patients, many of whom are on thalidomide. There are some other side effects, such as orthostatic hypotension, but those are the main ones.

Take care,

Jim