

MY REASON FOR PROSTATE CANCER ADVOCACY/MENTORING

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My spur to action as a prostate cancer advocate and mentor occurred when my cancer recurred in 1996, three years following earlier RP in December 1992 followed by EBRT the Spring of 1993 with Gleason Score 3+4=7. I initially delved into deep research and study of prostate cancer to insure my own appropriate care. But as I learned more, others began asking my advice as to understanding and treatment regarding their diagnostics. This spurred me even further to research and study since I felt I could not feel comfortable providing recommendations to patients for their own further research and discussion with their physician(s) without being confident that I had assembled sufficient reference material to back my recommendations. I then began attending national conferences on prostate cancer to personally meet as well as to listen to the presentations by physicians acknowledged to be top in the nation with expertise in various areas of treating our cancer. And when the opportunity arose, I participated two years in a row as a "Consumer Reviewer" (patient representative) on Congressionally Directed Medical Research Programs regarding, specifically, Prostate Cancer Research on panels with about nineteen research scientists to review research proposals submitted by other research scientists seeking funding for their prostate cancer research. This brought me into a world of science that is so important to we patients. The first year I served on a panel regarding Cell Biology; the second year on a panel regarding Physical Imaging (research in the use or improvement of imaging with, for example, MRI, CT, and CDU). To be in discussion with many of our top research scientists was so interesting and educational. This resulted in an impetus to even further personal research and study and now being able to at least better recognize medical terminology and application of science when reviewing the results of research and trials. And I became "obsessed." I just cannot back away from wanting to know more. And with more and more patients seeking my counsel, I found that it would ease my repetition of recommendations if I either authored, compiled, or posted papers from physicians that I could refer patients when asking for information regarding a particular area of prostate cancer. This information is now available on our Wichita, Kansas Chapter, Us TOO Intl., Inc. website www.ustoowichita.org under the index word "Observations." When patients access that webpage, they can just click on the subject wording and the information opens for review.

