

MY REASON FOR PROSTATE CANCER ADVOCACY/ACTIVISM

By Charles (Chuck) Maack – Prostate Cancer Patient/Activist/Mentor

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 my personal website www.theprostateadvocate.com. When patients access my website, they can just click on the menu word "Observations" and the information in alphabetical order opens for review.

And here is my “Disclaimer:”

DISCLAIMER: Please recognize that I am not a Medical Doctor. I have been an avid student researching and studying prostate cancer as a survivor and continuing patient since 1992. I have dedicated my retirement years to continued research and study in order to serve as an advocate for prostate cancer awareness, and, from a activist patient’s viewpoint, to voluntarily help patients, caregivers, and others interested develop an understanding of prostate cancer, its treatment options, and the treatment of the side effects that often accompany treatment. There is absolutely no charge for my mentoring – I provide this free service as one who has been there and hoping to make your journey one with better understanding and knowledge than was available to me when I was diagnosed so many years ago. Readers of this paper must understand that the comments or recommendations I make are not intended to be the procedure to blindly follow; rather, they are to be reviewed as my opinion, then used for further personal research, study, and subsequent discussion with the medical professional/physician providing your prostate cancer care.