

PROSTATE CANCER ADVOCACY AND MENTORING SUPPORT

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

The mission of a Prostate Cancer Advocate and Mentor should be to help men and their families make informed decisions about prostate cancer detection, treatment, and the side effects that accompany most forms of treatment.

As with most Prostate Cancer support organizations, we want to make sure patients have access to the programs, medications, treatments and health care professionals they need for the best possible outcomes.

That means as an Advocate as well as Mentor, I have an obligation to recommend to patients or their caregivers specific programs available to them, medications and treatment option considerations based on their diagnostics, and direct them to those health care professionals I am aware have expertise and positive outcomes to discuss these recommendations. Also, as a Mentor, it is my opinion I should not maintain a “neutral” stance avoiding any discussion regarding our disease or its treatment. As a prostate cancer survivor, continuing patient since 1992, and Mentor, I recommend specific Urologists, Medical Oncologists, Radiation Oncologists, and Pathologists of whom I am personally aware of their expertise regarding the treatment of prostate cancer as well as treatment of the side effects that accompany treatment options.

Having been involved in research and deep study of prostate cancer since 1996, attended national conferences on prostate cancer, participated on prostate cancer scientific research panels, as well as participated in an Innovative Minds in Prostate Cancer Today (IMPACT) gathering of 600 research scientists and 100 advocates/mentors like myself, I believe I am sufficiently aware of treatment and medications that should be considered but too often are not. When I find that being the case, I provide patients recommendations and reference material to study and empower themselves to then take to their physician(s) to discuss and determine appropriate treatment, or determine why a diagnostic test, treatment, or specific medications may not have been prescribed. Advocacy and/or Mentoring is more than encouraging prostate cancer awareness. It is my opinion that taking on the role of Mentor means involving oneself in research and deep study in order to support and assist patients who are seeking help to understand a particular concern or through the hurdles of understanding prostate cancer and its treatment options.

When I joined the Wichita, Kansas Chapter of Us TOO Intl., Inc. support group in 1996 I recognized that no member other than support group member Dr. Bob Husted, a retired anesthesiologist, had any knowledge beyond their own previous or current treatment, so were unable to address any other concerns of patients. When I began my research and study, Dr. Husted encouraged and pushed me to keep doing so to educate myself and learn as much as possible regarding several facets of treating our insidious disease. He was my mentor until he passed on from other health issues. Since his passing other highly regarded Medical Oncologists, Urologists, Radiation Oncologists, and Pathologists served as my mentors, though they were not even aware, through my study of their research and treatment recommendations. It didn't take me long to realize that every day something in medicine and in science changes, and with that realization I found I could only keep up by continuing my research and study and have done so all these years. I am on my computer at a minimum of six hours every single day, and more often more than that, involved in monitoring several scientific and medical websites, as well as several prostate cancer support lists, and addressing concerns of patients worldwide on those support lists or who have emailed or telephoned me directly seeking assistance. It was in having different patients asking me the same questions that prompted my development of my personal opinion "Observations" webpage on my personal prostate cancer website www.theprostateadvocate.com. There are currently over 200 different papers regarding the wide varieties of experiences that occur with prostate cancer that I refer patients to read and have a better understanding of the concern they are addressing, and that number of subjects will likely increase as new medications and new treatment options become known. Similarly, I have written and had published in Medical and Scientific Journals seventeen (17) papers regarding prostate cancer and its treatment.

I provide this lengthy explanation so readers will understand that as a prostate cancer advocate and mentor, I feel it my obligation to the patient or caregiver to endorse appropriate doctors, medical centers, and procedures. We are to provide patients whatever we have at our disposal to address any concern of a patient, and should we not have the answer at hand, we should help the patient find the answer. That being said, it is important for anyone reading this paper or any of my "Observations" to take note of the following:

DISCLAIMER: Please recognize that I am not a Medical Doctor. Rather, as a medical detective, 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 an activist patient's viewpoint and as a mentor, 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. **IMPORTANTLY**, 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.