

Advocacy and SUPPORT  
Charles (Chuck) Maack – Prostate Cancer Advocate/Activist/Mentor

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From: [www.ustoo.org](http://www.ustoo.org)

**“The mission of Us TOO is to help men and their families make informed decisions about prostate cancer detection and treatment through support, education and advocacy.....”**

and

**“We are committed to making sure patients have access to the programs, medications, treatments and health care professionals they need for the best possible outcomes.”**

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I purposely underlined this last sentence to bring attention that their statement directs that members of Us TOO are expected to make “sure patients have access to the programs, medications, treatments and health care professionals they need.”

In my personal opinion, that means as an Advocate 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, in my personal opinion, advocates should not maintain a “neutral” stance avoiding any discussion regarding our disease or its treatment. In that Us TOO does not agree in my personal opinion of what their Mission Statement implies, despite the wording of that mission statement, please take note that I do not write this paper representing Us TOO. As a prostate cancer survivor, continuing patient, and advocate, 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 often accompany treatment options.

Having been and continuing to be involved in research and deep study of prostate cancer since 1996, attending national conferences on prostate cancer, participating on prostate cancer scientific research panels, as well as participating in a

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 is more than encouraging prostate cancer awareness. It is my personal opinion that taking on the role of Advocate means advocates should 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 our support group in 1996 I recognized that no member other than support group member Dr. Bob Hustead, 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. Hustead 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 his death from other health issues. 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 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" page on my personal website [www.theprostateadvocate.com](http://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.

I provide this lengthy paper so readers will understand that as a prostate cancer advocate, 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. 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.