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# Foreword

Everyone agrees that, at present, there is no cure for prostate cancer, except early detection and some chance of removing the cancer entirely through early treatment. Until much more is understood about the disease and more money has been spent to determine not only how to cure it but what causes it, why not use the one procedure that works? *Early detection.*

This is not going to come about unless there is a cessation of the never-ending argument advanced by many professionals, namely, "Until we know screening can be *proved* to improve quality of life, we should not have screening." So the number of men diagnosed with prostate cancer continues to rise yearly, and there are too many naysayers blaming that on better and more frequent detection. Is it more important to satisfy the critics or is the issue saving lives?

Here is the challenge. We have to encourage those men who are in denial about their disease to come forward and help us in our struggle to save them. At the same time, we have to develop proactive efforts to offset the inertia of government regarding prostate cancer and seek positive action. Men must become as organized as the individuals in the breast cancer movement.

## Survey Reveals Gap in Patient-Physician Understanding

In the summer of 1995, US TOO! International, Inc., through a grant from Schering/Oncology Biotech, engaged Louis Harris & Associates to interview 1000 of its survivor-members and 200 urologists specializing in prostate cancer. US TOO! promulgates the view that patients should be educated in prostate cancer, should keep good records of treatments and test results, and should take responsibility for decisions regarding their caregivers.

The survey revealed that a high percentage of patients (79%) indicated they had taken an active role in the treatment process. Only 3% did not enter into the decision process.

Despite the fact that all patients interviewed were US TOO! members, there remained a discrepancy between the physician's feelings regarding the exploration of treatment options and the patient's recollection of these discussions.

Since the US TOO! survey was the first of this type ever undertaken, there has been increasing interest generated on the part of survivors, patient organizations, physicians, and professional organizations. Reactions from prominent urologists have been very positive, and there seems to be a good spirit of cooperation in wanting to improve patient-physician relationships and communication.

The goal of the US TOO! organization is to fully educate patients with prostate disease. A man with prostate cancer must be informed about all of his treatment options so that he can work with his physician to decide on the best course of therapy in his particular situation.

### The Importance of Screening Tests

Prostate cancer, which strikes about a quarter of a million men annually in the United States alone, is often without recognized symptoms in its early stages. Every 2 minutes a man is diagnosed with prostate cancer, and every 13 minutes a man dies of the disease. In the above-mentioned study, fully two thirds of all prostate cancer patients reported that they had no symptoms before they were diagnosed; physicians estimated that half of their patients on average had symptoms on diagnosis. According to the survey, more than half of all prostate cancer patients are first diagnosed with early-stage (stage A or B, T1 or T2) disease.

"The efforts to educate and screen the growing number of aging men have made an impact," says E. David Crawford, M.D., who was instrumental in founding Prostate Cancer Awareness Week. This annual campaign encourages yearly prostate cancer screening examinations for all men over age 50 and for men over age 40 if they have a family history of the disease.

### Discussing Treatment Options With Your Doctor

A clear majority of patients (84%) in the US TOO! survey reported that they had discussed treatment options with their physicians. Although more than 80% of the patients surveyed cited preserving quality of life and delaying disease progression as the main benefits they seek in treatment, physicians consistently thought that survival was the primary concern of their patients. These differences suggest the need for improved communication and collaboration between physicians and patients. While only a minority of patients (8%) were uneasy talking with their doctors, prostate cancer was three times more pronounced in African-American men than in Caucasian men. The disease is particularly aggressive in black men.

"Given the number of options available and the ongoing debate about prostate cancer treatments, patients can seek information not only from their physicians but also social workers, psychologists, and patient advocacy

groups who can provide information, education, and support," says Marc B. Garnick, M.D., Associate Clinical Professor of Medicine, Dana-Farber Cancer Institute, a teaching affiliate of the Harvard University Medical School.

### Side Effects Are a Patient Concern

Physicians surveyed actually recommended intervention or therapy for only two thirds of their early-stage patients and the less aggressive approach of monitoring the disease or watchful waiting for one third of their patients.

For 45% of the patients surveyed, preserving quality of life is the most important benefit of any treatment. What does this mean? Among prostate cancer patients who face some form of treatment, three key issues stand out: preservation of life, short- or long-term incontinence, and potential impotence. Each patient will place a different priority on the outcome of his treatment, but after preservation of life, there is great concern for quality of life, such as fear of long-term incontinence or impotence.

The US TOO! survey clearly shows greater awareness and activity on the part of prostate cancer patients. But there is much more to be done. Patients must seek information, talk more directly to their doctors, deal with the emotional aspects of their treatments, and take an active role in managing their disease. Their best option is active participation in a support organization such as one of the more than 500 US TOO! prostate cancer support groups.

Henry A. Porter field