

FOR THE RECORD

House of Representatives
Committee on Oversight and Government Reform

Hearing on:
“Prostate Cancer: New Questions About Screening and Treatment”

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Statement Submitted for Consideration by the Committee

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**Testimony of
Women Against Prostate Cancer**

Women Against Prostate Cancer (WAPC) would like to thank Chairman Towns and the Committee for holding this important hearing. We appreciate the opportunity to submit testimony on a topic that has a significant impact on our constituents and thousands of other men, women and families.

The mission of Women Against Prostate Cancer is to unite the voices and provide support for the millions of women affected by prostate cancer. As health care leaders of the household, the role that women play in all phases of prostate cancer from preventive screenings to treatment and follow-up care is critical.

Our membership is made up of wives, partners, mothers, daughters, sisters, widows, caregivers, healthcare professionals and advocates who have been touched by prostate cancer. Below we have shared stories from a few of our members that express the essential role that women play in the lives of the men they love when diagnosed with prostate cancer:

- Betty Gallo of NJ: When Betty's husband, former Congressman Dean Gallo, was diagnosed with prostate cancer in 1992, the PSA, so widely used today for diagnosing prostate cancer, was not utilized. "Dean went to the doctor for back pain," Betty shares, "But by then it was too late. The cancer had already spread to his bones." Unfortunately Dean did not survive his battle, but Betty continues on as a dedicated advocate who wants to make sure no man or woman has to experience the frustration and lack of resources that they had.
- Kathy Meade of Virginia: "Together we fought an aggressive and valiant fight against his cancer, working as a team to understand his disease and treatment options, and face difficult choices. He knew he was the ultimate decision maker, but he deferred to me for information, analysis and common sense."
- Gail Puffer of Connecticut: When her husband was diagnosed she "gathered information, organized lab work and office visit notes, and explored treatment options." She said, "The doctors loved that I have done some research. My familiarity with terms made us more conversant and better informed." Gail expresses some additional needs to help prostate cancer patients and families, "We also need to know more about what to expect when first diagnosed. If added to the treatment team, trained professionals, such as social workers, nurses or therapists, can help us get over some of the hurdles." She also shares, "due to my husband's diagnosis my concerns are now very much with my sons who are at an increased risk for the disease," indicating her continued concern for better early detection methods.
- Sherrie Ellenburg of North Carolina: "In December 2003, the doctors concluded that Kenny's cancer was too advanced for surgery. At 42 years of age, his only treatment option was radiation with hormone therapy." "He did his part by encouraging his family and friends to have their yearly exams. His brother, Bryan, was his first success story when a year after Kenny's death he was diagnosed through early detection." Unfortunately Kenny did not survive his disease, but Sherrie remains a very active advocate and expresses, "My biggest frustration throughout this ordeal was dealing with the finances. The financial struggles that we faced were so insurmountable at times I did not know how we would

make it. We were thankful for every day we had together. However, instead of enjoying those last moments, we had to focus on how to provide the basics – food, electricity, and pay our mortgage – with no income. We applied for disability but were repeatedly denied. Finally, six months before his death he was approved. It was amazing to see how his quality of life improved! The struggle of treatment is a painful enough journey without the added financial pressures, such as we had to endure.”

These are just a few of the stories we hear everyday that express the critical role that women play and how prostate cancer significantly impacts the entire family.

In addition to our testimony outlined below, we fully support the group testimony submitted by America’s Prostate Cancer Organizations. As a collaborative partner in the group we share the goal that all such men should receive the most appropriate advice and care, and that we continue to limit the devastating impact of prostate cancer on men and their families.

We wish to express the following concerns for the Committee to consider:

- Prostate cancer is a complex and problematic disease that affects not only the male patient but can also be devastating to his wife or partner and other family members over many years. Nearly 200,000 men will be diagnosed with prostate cancer in 2010, and about 28,000 will die from this disease. With Approximately 2 million men currently living with prostate cancer, there are countless partners, spouses and loved ones who are also suffering from the effects of this disease. In addition, we are concerned about the reported increase in the percentage of younger men (35 – 60 years old) being diagnosed with metastatic prostate cancer which has lead to increased strain and stress placed on families with young children who in many cases will grow up without a father.
- More support and education is needed for partners, caregivers and the entire family when a man is diagnosed with prostate cancer. Women play a very important role in the screening, diagnosis, treatment and recovery phases of prostate cancer.
 - As health care leaders of the household, women often provide the extra encouragement and reminders that men need to make an appointment with a physician for regular check-ups, prostate exams or when symptoms appear.
 - Women often attend doctor’s appointments with their loved ones to provide support, ask questions and take notes.
 - If diagnosed with prostate cancer, there may be several treatment options and partners and spouses often play an important role in researching the options and helping their loved one decide which option is best for them.
- The early detection and appropriate treatment of clinically significant and potentially lethal prostate cancer remains a critical priority, especially among men at high risk because of family history, ethnicity, or other factors that define such risk.
 - African-American men have one of the very highest rates of incidence and death from prostate cancer anywhere in the world. The increased rates in this community have a significant impact on the spouses and families of those with the disease.
 - Every man has the right to know whether he is at risk for potentially lethal prostate cancer.
 - Experts disagree on the adequacy and usefulness of PSA and DRE testing to identify men at risk for potentially lethal prostate cancer.
 - Physicians and their adult male patients should be encouraged to discuss the patients’ personal risks for prostate cancer and the individual need for prostate cancer testing at each patient’s annual physical exam.

- Men at higher levels of risk for prostate cancer (because of ethnicity, family history, and other factors) should be encouraged to undergo appropriate tests at a relatively early age.
- Additional funding is needed to increase outreach and promotion of clinical trials. These trials provide crucial information to researchers and experts on better screening, detection and treatment options. NCI should provide grants to provide outreach for clinical trials.
- Until more accurate tests are available, all health care insurance plans should include coverage for annual tests for prostate cancer (including the prostate-specific antigen or PSA test and the digital rectal examination or DRE) – and follow-up diagnostic testing when appropriate. The PSA is not a perfect test, but it is all we have right now.
- Additional funding is urgently needed to support research into better ways to identify and discriminate between very low risk (“indolent”) and higher risk (clinically significant and potentially lethal) forms of prostate cancer at the time of diagnosis and into better forms of management for patients with or at risk for potentially lethal disease.
 - Most specifically, we support a significant increase in funding for the Prostate Cancer Research Program (PCRP) of the Congressionally Directed Medical Research Program (CDMRP) at the Department of Defense, which has been funded at \$80 million each year since 2001. We would like to see this funding increased to \$125 million per year in order to continue and increase the important research that is being done.
- We continue to support the need for an Office of Men's Health (HR 2115), comparable to the highly successful Office of Women's Health, within the Department of Health and Human Services (HHS) that can represent the specific health interests of men and their families.

In conclusion, we would like to thank the Committee for all of its work on this issue and allowing the opportunity for patient organizations like ours to provide input into a discussion whose outcome will impact thousands of men, women and their families across the country.