FOR THE RECORD

House of Representatives
Committee on Oversight and Government Reform

Hearing on:
"Prostate Cancer: New Questions About Screening and Treatment"

10:00 a.m.
Rayburn 2154

Thursday, March 4, 2010

Statement Submitted for Consideration by the Committee

Betty Gallo
Co-Founder

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Committee on Oversight and Government Reform

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Testimony of
Betty Gallo, Co-Founder, Women Against Prostate Cancer

I would like to thank Chairman Towns and the Committee for holding this important hearing. I appreciate the opportunity to submit testimony on a topic that has had a significant impact on my own life and on the lives of thousands of other men, women and families.

Women Against Prostate Cancer's mission 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.

My husband, former Congressman Dean Gallo, was diagnosed with prostate cancer in 1992. He went to the doctor for back pain, but what they discovered was prostate cancer that had already spread to his bones.

The PSA was not a widely used test at that time, and had he received this simple screening in time, he might still be here today. When his cancer was detected his PSA level was 882, much higher than the normal range of 1 to 4.

Given only a few months to live, Dean enrolled in several experimental therapies, some of which helped, but only for a short time.

Throughout his diagnosis and treatment Dean remained committed to serving the people that he faithfully represented and I am committed to follow in his footsteps and make sure more is done to end the suffering that thousands of men, women and families experience from this devastating disease.

In addition to my own experience, members of Women Against Prostate Cancer share their heartbreaking stories with me everyday and I would like to share just a couple with you now:

- When Gail Puffer's 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 that, "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 shared that "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 I hear everyday that express the critical role that women play and how prostate cancer significantly impacts the entire family.

I would like to express the following concerns for the Committee to consider:

- 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. 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.

- Early detection and appropriate treatment of prostate cancer remains a critical priority, especially among men at high risk because of family history, ethnicity, or other factors that define such risk.

    - Physicians and male patients should be encouraged to discuss the patients’ personal risks for prostate cancer and the individual need for prostate cancer testing.
    - Men at higher levels of risk for prostate cancer, including African American men and men with a family history, 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.

- The PSA is not a perfect test, but it is all we have right now. Until more accurate tests are available, all health care insurance plans should include coverage for annual tests for prostate cancer (including the PSA test and the digital rectal examination) – and follow-up diagnostic testing when appropriate. And these screenings should be included in any health reform legislation. If the PSA had been available when Dean, he would not have died from advanced prostate cancer.

- Additional funding is urgently needed to support research into better ways to identify low risk versus higher risk forms of prostate cancer at the time of diagnosis. More specifically, an increase in funding for the Prostate Cancer Research Program (PCRP) of the Congressionally Directed Medical Research Program (CDMRP) at the Department of Defense. Funding should be increased to $125 million from the current level of $80 million in order to continue and increase the important research that is being done.

- The creation of 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) is critical and can represent the specific health interests, like prostate cancer, of men and their families.

For the past 15 years I have been so involved in advocacy for prostate cancer. It has helped me through the grieving process and knowing I have been able to help other men, women and their families. As men and women in Congress, you are aware of what prostate cancer does to families and have experienced the loss of several colleagues to this disease. The most important issue is education.

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

I am attaching the statement from Women Against Prostate Cancer below as part of my testimony.

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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.

FOR THE RECORD

Addendum to the testimony of:

Betty Gallo

Consisting of the following statements:

America's Prostate Cancer Organizations

Men's Health Network

MaleCare

Committee on Oversight and Government Reform

Full Committee Hearing on:

"Prostate Cancer: New Questions about Screening and Treatment"

Thursday, March 4, 2010

10:00 a.m.

Room 2154, Rayburn House Office Building

House Committee on Oversight and Government Reform

(Chairman: Ed Towns, D, NY)

Hearing on

"Prostate Cancer: New Questions About Screening and Treatment"

March 4, 2010

Joint Statement of

America's Prostate Cancer Organizations

comprising

Malecare Prostate Cancer Support
www.malecare.com

Men's Health Network
www.menshealthnetwork.org

National Alliance of State Prostate Cancer Coalitions
www.naspcc.org

Prostate Cancer Foundation
www.pcf.org

Prostate Cancer International
www.pcainternational.org

Prostate Conditions Education Council
www.prostateconditions.org

Prostate Health Education Network
www.prostatehealthed.org

The Prostate Net
www.theprostatenet.org

Us TOO International Prostate Cancer Education and Support Network
www.ustoo.org

Women Against Prostate Cancer
www.womenagainstprostatecancer.org

ZERO – The Project to End Prostate Cancer
www.zerocancer.org

With Support From:

RetireSafe
www.retiresafe.org

Veterans Health Council
www.veteranshealth.org

Vietnam Veterans of America
www.vva.org

House Committee on Oversight and Government Reform

Hearing on

"Prostate Cancer: New Questions About Screening and Treatment"

March 4, 2010

Joint Statement of

America's Prostate Cancer Organizations

Collectively, America's Prostate Cancer Organizations thanks the Committee on Oversight and Reform for holding this important hearing, and we appreciate the opportunity to submit joint testimony on the critical issues that affect the current status of the prevention, diagnosis, and treatment of prostate cancer, and research into all aspects of this disease.

America's Prostate Cancer Organizations is a collaborative group of independent not-for-profit organizations that seek to represent the best interests of men at risk for, diagnosed with, and treated for prostate cancer in America today. Our shared goal is 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.

America's Prostate Cancer Organizations counts among its collaborators:

- The largest network of prostate cancer patient support groups in the world
- The world's largest, independent, not-for-profit organization involved in raising money to support prostate cancer research
- Organizations that represent the interests of specific underserved and special interest groups, including African Americans and the gay community

Our fundamental objective in presenting this testimony is to offer the committee some guidance on current priorities -- as seen from the point of view of the men at risk for prostate cancer, patients with this disease, and the families of men who either have prostate cancer today or have passed away as a consequence of this disease.

Our testimony is brief and to the point, and demonstrates to the Committee the shared perspective of literally tens of thousands -- if not millions -- of men and their families across America.

We wish to make just five important observations, and we ask the Committee to consider these observations with great care:

- Prostate cancer is a complex and problematic disease that affects not only the male patient but also his wife or partner and other family members over many years. Nearly 200,000 men will be diagnosed with prostate cancer in the U.S. in 2010, and about 28,000 will die from this disease.

- 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.

    - 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 currently available tests to identify men at risk for potentially lethal prostate cancer early enough to offer curative therapy.

    - African-American men have one of the very highest rates of incidence and death from prostate cancer anywhere in the world.

    - 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.

- Until more accurate tests are available, all health care insurance plans should include coverage of regular testing for prostate cancer (including the prostate-specific antigen or PSA test and the digital rectal examination or DRE) – and its subsequent diagnosis.

- 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 continue to support the need for an Office of Men's Health (comparable to the highly successful Office of Woman's Health) within the Department of Health and Human Services (DHHS) that can represent the specific health interests of the male population of America.

In conclusion, we thank the Committee for its efforts and its leadership in many aspects of health care, and specifically for presenting this opportunity for the many issues affecting the prevention, diagnosis, and management of prostate cancer (and its clinical consequences) to be discussed in this public forum.

FOR THE RECORD

Committee on Oversight and Government Reform

Full Committee Hearing on:

"Prostate Cancer: New Questions about Screening and Treatment"

Thursday, March 4, 2010

10:00 a.m.

Room 2154, Rayburn House Office Building

Statement Submitted for Consideration by the Committee

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Committee on Oversight and Government Reform

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March 4, 2010

Statement of Men's Health Network (MHN)

On behalf of Men's Health Network we applaud the Committee's decision to hold hearings on this critical health issue.

We also support the joint statement from America's Prostate Cancer Organizations which was submitted to this committee. MHN's additional recommendations are found on page 4 of this statement. Supportive materials begin on page 6.

Impact on Women and Families:

Prostate cancer does not affect men in isolation. Spouses, significant others, and children are too often emotionally, financially, and physically strained, and the diagnosis reaches beyond the family to impact friendships, employers, churches, and communities.

Prostate Cancer Incidence

Prostate cancer is the number one cancer in men and the second leading cause of cancer deaths among men. 37 states currently require private insurers to cover testing for prostate cancer, reflecting the public's concern about this issue. As this disease continues to strike one in six American men, it is important that patients and physicians engage in a meaningful conversation about prostate cancer, an individual's risk of getting the disease, and the value of early detection and prevention.

Screening/Detection/Treatment

Because of regular screening, including Prostate Specific Antigen (PSA) tests, prostate cancer death rates have fallen significantly. Prostate Specific Antigen (PSA) and the Digital Rectal Exam (DRE) are currently the most effective tools healthcare providers and patients have to detect a disease that kills over 27,000 men a year in the US.

Prostate cancer screening is particularly important for those segments of the population and individuals who are identifiable as high risk, including African American men and men who have a family history of prostate cancer.

Recognizing that prostate cancer can be treated successfully if caught early, the American Urological Association currently recommends that men consider a "baseline" prostate cancer test at age 40.

In addition to the approximately 200,000 men who are diagnosed with prostate cancer each year, we must remember that the disease can have a devastating effect on entire communities.

The detection and treatment of prostate cancer is a variable process, involving a number of important factors and requiring knowledge and understanding by both men and their healthcare providers. Important research progress is being made in developing better, more specific diagnostic tools for prostate cancer. However, until we have them at our disposal, we need to bring clarity to the debate, and continue utilizing the tests and tools we have while informing patients and their families about the benefits of screening and the risks involved with various treatments.

Prostate cancer testing has been supported by a resolution of the Democratic National Committee in September 2009 and by President Obama in a town hall meeting and again in a Weekly Address on August 15, 2009 (see appendix below). President Obama said that he would "require insurance companies to cover routine checkups and preventive care" so that "diseases like breast cancer and prostate cancer" can be detected early.

Patient Navigation / Education / Informed Treatment Decisions

Patient navigation and education are key elements in helping patients with their fight against prostate and other cancers. Even well-educated patients with access to resources often have difficulty understanding the labyrinth of medical care and treatment options in the face of prostate cancer. Patient navigators are essential to helping patients make informed decisions and understand the options for treatment, and possible outcomes.

Patient navigation has also been shown to be effective in reducing disparities, as well as mortality rates.

We acknowledge the key role that oncology nurses and nurse navigators, physician assistants, nurse practitioners, and many others play in the health and well-being of men and their families.

Healthcare Reform / USPSTF

We are concerned that the health care needs of males, and the prostate cancer community, are not adequately addressed in healthcare reform legislation currently being considered. Men's health and well-being has a crucial financial and social impact within American families and communities. This impact is highlighted by an Administration on Aging study which found that more than half the elderly widows living in poverty were not poor before the death of their husbands.[1]

According to the United States Census Bureau, the ratio of men to women in the early retirement years (age group 65-69) reduces to 85 men per 100 women.[2] The growing disparity in this statistic suggests that among other factors, the declining health of men increases the risk of women entering retirement age as widows.

[1] Meeting the Needs of Older Women: A Diverse and Growing Population, The Many Faces of Aging, U.S. Administration on Aging. June 20, 2001

[2] Premature Death Among Men = Poverty for Aging Women, found at www.menshealthnetwork.org/library/retireratio.pdf

We also understand that health disparities exist and that Healthy People 2010 made one of its core issues the elimination of gender disparities, a goal largely unrealized over the past 10 years. Across all racial and ethnic categories, American men live less healthy lives and die younger than American women. Engaging men in health care has enormous benefits for women, children, and society.

Recent changes in national guidelines and standards for mammography screenings from the United States Preventive Services Task Force (USPSTF) have caused a flurry of discussion around the role of the Task Force. Men's Health Network has monitored their recommendations closely for many years and is concerned that the USPSTF does not recommend prostate cancer testing even while the use of the DRE and PSA continues to save lives.

We are also concerned that the recommendations of the USPSTF will override the prostate cancer testing benefit required of insurance companies in 37 states (and currently available to millions of men across the country), the life-saving benefits offered to those entering Medicare, the wishes of the Democratic National Committee, and the promises made by the President of the United States, Barack Obama.

We are concerned that the failure to recognize the benefits of early detection of prostate cancer (and breast cancer) will result in the unnecessary suffering of cancer victims and their families.

Recommendations:

In addition to the concerns expressed in the joint statement submitted by America's Prostate Cancer Organizations, we offer the following suggestions:

- *Health Reform Legislation*. A comprehensive preventive health care screening package for men that mirrors the preventive health screening package for women that was added to the Senate health reform bill is a top priority.

- *Office of Men's Health*. We support HR 2115, bipartisan legislation which would establish an Office of Men's Health within the Department of Health and Human Services for the purpose of improving the health of men and their families. This Office will mirror the existing Office of Women's Health, established in the early 1990s, which has improved the quality of life for women nationwide.

  The Office of Men's Health will be designed to monitor and coordinate efforts to improve the health and well-being of men by streamlining government efforts on the federal and state levels in the areas of prevention, health education, outreach, and research. The office would conduct and support programs and activities to improve the state of men's health in the United States. It would provide for consultation among offices and agencies of HHS for the purpose of coordinating public awareness, education, and screening programs and activities relating to men's health.

- *Least Costly Alternative (LCA)*. We urge Congress to demand that the Centers for Medicaid & Medicare Services (CMS) rescind the Least Costly Alternative policy for prostate cancer drug therapies to ensure patients have equitable access to vital drug

treatments. This policy drives healthcare providers to make treatment decisions based on cost, rather than clinical factors.

LCA unfairly singles out prostate cancer patients, disproportionately affects low-income patients, and does not apply to other conditions. LCA policies for prostate cancer drugs are inappropriate because they substitute Medicare's determination that certain drugs are interchangeable for the physician's professional judgment that one drug may be more efficacious or have fewer side effects for a particular patient. LCA is not provided for in statute, Furthermore, the District of Columbia Appellate Court has ruled that this is not based in law, and CMS does not have statutory authority to continue the least costly alternative policy. Therefore, we call on Congress to abolish this unfair and unjust rule that disenfranchises prostate cancer patients

- *Research*. We have some of the brightest minds in this country working on research and development of breakthrough therapies, tests, and treatments for prostate cancer, but they are drastically underfunded. We need to find better ways to support these efforts, while continuing to keep our focus on improving the lives of patients and their families. We are close to significantly moving the needle in the prevention, treatment, and management of prostate cancer for men and their families. As a nation we should be committing resources and expertise toward ensuring the continuation of these exciting new developments.

- *Treatments Options / Innovation*. Cutting edge research and development and novel innovative discoveries will lead to new treatment options for advanced stage disease as well as opportunities for prevention and earlier detection of prostate cancer. We should *Fast Track* new therapies through FDA to facilitate the development and expedite the review of drugs and treatments that will help improve the lives of victims of prostate cancer.

  The utmost should be done to support public education campaigns to inform men and their families of new treatment options, tests, and risk reduction and/or prevention therapies for prostate cancer when they become available.

Appendix

State requirements on insurance providers:

Currently 37 jurisdictions require that insurance companies operating in those states provide coverage for prostate cancer tests. A July 17, 2009 letter to this Committee on this issue, signed by the majority of prostate cancer advocacy organizations, is attached. (Arkansas became the 37th earlier this year, joining the 35 states and the District of Columbia mentioned in the accompanying letter to the Committee.)

A total of 50 jurisdictions, 49 states and the District of Columbia, require the same benefit for breast cancer screening (mammograms), Utah being the exception.

Role of the USPSTF:

Secretary Sebelius stated in her November 18, 2009 comments on the new breast cancer screening recommendations:

> "The U.S. Preventive Task Force is an outside independent panel of doctors and scientists who make recommendations. They do not set federal policy and they don't determine what services are covered by the federal government."

But, under the health care bill passed by the House of Representatives and the bill passed by the Senate, the USPSTF will do exactly that: determine which services are covered by a public plan offered by federal government while setting minimum standards for private insurance policies – thereby effectively overriding the prostate cancer test wishes of 37 state legislatures.

This language from HR 3962 as passed by the House of Representatives on November 16, 2009:

> Sec. 222. Essential Benefits Package Defined.
> (a) In General- In this division, the term `essential benefits package' means health benefits coverage, consistent with standards adopted under section 224, to ensure the provision of quality health care and financial security, that--
> . . .
> (8) **Preventive services, including those services recommended with a grade of A or B by the Task Force on Clinical Preventive Services** and those vaccines recommended for use by the Director of the Centers for Disease Control and Prevention.
> . . .
> (1) **No Cost-Sharing For Preventive Services** - There shall be no cost-sharing under the essential benefits package for--
> (A) **preventive items and services recommended with a grade of A or B by the Task Force on Clinical Preventive Services** and those vaccines recommended for use by the Director of the Centers for Disease Control and Prevention; or. . . .

The “Task Force on Clinical Preventative Services” will consist of the members of the USPSTF and others, and the current recommendations of the USPSTF will be the initial recommendations of the “Task Force on Clinical Preventative Services”:

> `Subtitle G--General Provisions
> `SEC. 3171. Definitions.
> `In this title:
> . . . . . .
> (b) Transition Provisions Applicable to Task Forces-
> (1) Functions, Personnel, Assets, Liabilities, And Administrative Actions- All functions, personnel, assets, and liabilities of, and administrative actions applicable to, the Preventive Services Task Force convened under section 915(a) of the Public Health Service Act and the Task Force on Community Preventive Services (as such section and Task Forces were in existence on the day before the date of the enactment of this Act) shall be transferred to the Task Force on Clinical Preventive Services and the Task Force on Community Preventive Services, respectively, established under sections 3131 and 3132 of the Public Health Service Act, as added by subsection (a).
> (2) **Recommendations- All recommendations of the Preventive Services Task Force** and the Task Force on Community Preventive Services, **as in existence on the day before the date of the enactment of this Act, shall be considered to be recommendations of the Task Force on Clinical Preventive Services and the Task Force on Community Preventive Services, respectivel**y, established under sections 3131 and 3132 of the Public Health Service Act, as added by subsection (a).
> (3) Members Already Serving-
> (A) **Initial Members**- The Secretary of Health and Human Services may select those **individuals already serving on the Preventive Services Task Force** and the Task Force on Community Preventive Services, as in existence on the day before the date of the enactment of this Act, **to be among the first members appointed to the Task Force on Clinical Preventive Services** and the Task Force on Community Preventive Services, respectively, under sections 3131 and 3132 of the Public Health Service Act, as added by subsection (a).

President Obama addresses the need for early detection of breast and prostate cancer:

The availability of tests, while not perfect, which can identify cancer in an early stage is certainly responsible for the increased detection of early stage, treatable prostate cancer and breast cancer, and the dramatic reduction in deaths from those cancers over the past two decades.

Those tests should be made available so that we might continue to identify cancers while they are treatable, thereby saving the lives of mothers, fathers, brothers, sisters, husbands, wives, and other loved ones.

President Obama promised as much in his weekly address of August 15, 2009:

> "Finally, we’ll require insurance companies to **cover routine checkups and preventive care**…because there’s no reason we shouldn’t be saving lives and dollars by catching diseases like **breast cancer and prostate cancer** on the front end."

This followed a similar statement he made at the Town Hall meeting in Portsmouth, New Hampshire on August 11, 2009

The Democratic National Committee calls for prostate cancer screening and tests:

The President's commitment was reinforced by the Democratic National Committee at the DNC Annual Meeting in Austin held over September 10-12, 2009 in a resolution which concluded:

> Therefore Be It Resolved, that the Democratic National Committee urges action to promote prostate cancer screening and testing

That resolution in support of prostate cancer testing is attached to this statement.

The "Welcome to Medicare" physical provides for prostate cancer screening tests:

As to Medicare, Congress has provided an excellent prostate cancer screening benefit, available to any man aged 50 and above who is enrolled in the program:

> Title 42--The Public Health And Welfare - Chapter 7--Social Security
> Sec. 1395x. Definitions
> . . . . .
> (oo) **Prostate cancer screening tests**
> (1) The term ``prostate cancer screening test'' means a test that consists of any (or all) of the procedures described in paragraph (2) provided for the purpose of early detection of prostate cancer **to a man over 50 years of age** who has not had such a test during the preceding year.
> (2) The procedures described in this paragraph are as follows:
> **(A)** A digital rectal examination.
> **(B)** A prostate-specific antigen blood test.
> **(C)** For years beginning after 2002, such other procedures as the Secretary finds appropriate for the purpose of early detection of prostate cancer, taking into account changes in technology and standards of medical practice, availability, effectiveness, costs, and such other factors as the Secretary considers appropriate.
> . . . . .
> (ww) Initial preventive physical examination
> (1) The term **``initial preventive physical examination''** means physicians' services consisting of a physical examination (including measurement of height, weight, and blood pressure, and an electrocardiogram) with the goal of health promotion and disease detection and includes education, counseling, and referral with respect to screening and other preventive services described in paragraph (2), but does not include clinical laboratory tests.
> **(2) The screening and other preventive services described in this paragraph include the following:**
> . . . . .
> **(D) Prostate cancer screening tests as defined in subsection (oo) of this section.**

Democratic National Committee

September 10-12, 2009

Resolution Urging Action to Promote
Prostate Cancer Screening and Testing

WHEREAS, one in every six men in the United States will be diagnosed with prostate cancer; and,

WHEREAS, nearly 30,000 men in the United States will die of prostate cancer this year; and,

WHEREAS, nearly 200,000 men in the United States will be diagnosed with prostate cancer this tear; and,

WHEREAS, prostate cancer is the second most common cancer in American men; and,

WHEREAS, Senator Chris Dodd was recently diagnosed with prostate cancer and received timely treatment because of early detection; and,

WHEREAS, the American Urology Association recommends prostate cancer screenings such as PSAs and other diagnostic tools as part of a detection and treatment protocol;

THEREFORE BE IT RESOLVED, that the Democratic National Committee urges action to promote prostate cancer screening and testing

July 17, 2009

The Honorable Henry Waxman
Chairman
Energy and Commerce
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Joe Barton
Ranking Member
Energy and Commerce
2322-B Rayburn House Office Building
Washington, DC 20515

Dear Representatives,

The undersigned organizations commend Congress and the Administration for seeking ways to extend health benefits to all Americans, and to make prevention the cornerstone of that effort. However, we are concerned that the health care needs of males, and the prostate cancer community, are not adequately addressed in the legislation currently being considered. We are also concerned that these bills appear to preempt state benefit laws that now require private insurers to provide a number of critical services, including tests for prostate cancer, the number one cancer in men.

Men's health and well-being has a crucial financial and social impact within American families and communities. This impact is highlighted by an Administration on Aging study which found that more than half the elderly widows living in poverty were not poor before the death of their husbands.[3] We also understand that health disparities exist and that Healthy People 2010 made one of its core issues the elimination of gender disparities.

Across all racial and ethnic categories, American men live less healthy lives and die younger than American women. Engaging men in health care has enormous benefits for women, children, and society.

Specifically, we encourage language within the final health reform legislation that will address these concerns:

- Current state mandates on health insurance coverage must be honored. The Essential Benefits Package as presently written (in the House bill) will offer only those preventive services actively recommended by the US Preventive Services Task Force (USPSTF). However, the USPSTF does not recommend many services now required by many different states. As just one example, at least 36 states require private insurers to cover testing for prostate cancer. The 2006 Census estimates found over 35 million men between the ages of 40 and 64 in those 36 states. Those 35 million men now have coverage for prostate cancer testing if they have health insurance. They will not be covered under the Essential Benefits Package unless state mandates are honored, and would therefore lose their right to understand their potential for risk of the most prevalent form of cancer in men
- The Senate and House bills each establish means whereby government will determine how best to proceed with prevention and wellness activities in both the private and public sectors. In making these determinations, advice will be sought by the heads of various agencies, including the Office on Women's Health.

  This highlights the need for an Office on Men's Health to advise, recommend and direct wellness and prevention efforts for men and boys.

[3] Meeting the Needs of Older Women: A Diverse and Growing Population, The Many Faces of Aging, U.S. Administration on Aging. June 20, 2001

Signed:

Accelerate Progress
Malecare
Men's Health Network
National Alliance of State Prostate Cancer Coalitions
Out With Cancer – The LGBT Cancer Project
Prostate Cancer International
Prostate Cancer Foundation
Prostate Conditions Education Council
Prostate Health Education Network
The Prostate Net
Us Too International
Women Against Prostate Cancer
Zero – The Project to End Prostate Cancer

State Organizations:
Alaska - Alaska Prostate Cancer Coalition
Arkansas - Arkansas Prostate Cancer Foundation
California - California Prostate Cancer Coalition
Colorado – PCEC Colorado Coalition
Connecticut - Prostate Cancer Education Forum of Connecticut
Georgia - Georgia Prostate Cancer Coalition
Hawaii - Hawaii Prostate Cancer Coalition
Kansas - Kansas Prostate Cancer Coalition
Kentucky - Kentucky Prostate Cancer Coalition
Maine - Maine Coalition to Fight Prostate Cancer
Maryland - Maryland Prostate Cancer Coalition
Michigan - Prostate Cancer Coalition of Michigan
Nevada - Nevada Prostate Cancer Task Force
New Hampshire - New Hampshire Prostate Cancer Coalition
New Jersey - Prostate Cancer Coalition of New Jersey
New York - New York State Prostate Cancer Coalition
North Carolina - Prostate Cancer Coalition of North Carolina
Pennsylvania - Pennsylvania Prostate Cancer Coalition
Pennsylvania - Obediah Cole Foundation for Prostate Cancer
Texas - Texas Prostate Cancer Coalition
Virginia - Virginia Prostate Cancer Coalition
West Virginia - Dan Blue Prostate Cancer Foundation

For the Record

To: The House Committee on Oversight and Government Reform

Re: Hearing on "Prostate Cancer: New Questions About Screening and Treatment"

March 4, 2010

We wish to thank the Committee for allowing us to present four important issues, on behalf of the thousands of men, their loved ones and their families, whom Malecare serves.

Founded in 1998, Malecare is our country's first and leading Gay men's cancer survivor support group and advocacy national nonprofit organization. All who work for Malecare are volunteers. Malecare publishes the worlds' largest multi-lingual prostate cancer focused website, malecare.org and several online support groups. Malecare is noteworthy for facilitating the largest grass roots prostate cancer survivor advocacy effort in over ten years. The Petition to make Prostate Cancer a National Priority currently has over 16,300 signatures of Americans who ask this Committee to increase federal funding for prostate cancer research.

Malecare has four unique programs, focused on men diagnosed in their thirties and forties, African American men, Gay men and men diagnosed with advanced disease, relevant to the Committee's discussion on prostate cancer screening and treatment.

Malecare's "Prostate Cancer under 50" is our country's only psycho-social support program for men diagnosed in their thirties and forties. We've seen approximately 700 men benefit from our program, with more men enrolling every day. From our experience, we can suggest that men diagnosed in their thirties and forties are more likely to die than men diagnosed later in later years. We ask the Committee to support promotion of prostate cancer information to all men from age 35 and up, during medical consultations.

Our New Dad program teaches patenting skills young African American experiencing their first child. Integrated in our parenting skills workshops and website is the need for early vigilance around health care. Mixed messages about screening and access to healthcare diminish our capacity to help young African American men find reason to ask about prostate cancer during personal medical consultations. We ask the Committee to support promotion of prostate cancer awareness in our African American community.

Malecare is our country's only national nonprofit focused on psycho-social support for men with advanced and terminal stage prostate cancer. Advanced prostate cancer is not curable. Approximately 27,000 American men died from prostate cancer in 2009 and comparable numbers will continue to die, every year, until there is a durable, morbidity free treatment or cure.

End stage treatments present debilitating morbidity and degrees of hope measured in days, weeks and months. Often, men learn of drugs and treatment protocols that might help, but are not yet available as they wait for outcomes of clinical trials and FDA approval. We ask the Committee to work with the FDA to create a mechanism for early and compassionate access to investigational or yet to be approved drugs and treatment protocols.

Current debate seems to have shifted focus towards those who live with their disease rather than those men who die from their disease. We need to refocus our consideration of prostate cancer towards helping those most likely to die from prostate cancer. We ask the Committee to support increased funding and promotion for research into end stage treatment.

Approximately 10% of all American men diagnosed with prostate cancer are men who have sex with men. Malecare is our country's only cancer survivor support and advocacy national nonprofit focused on gay and bisexual men, and transgender women. Prostate cancer presents unique and only recently understood psycho-social challenges for gay men. Unfortunately, we are still in the dark about the disparities of prostate cancer incidence and outcomes of homosexual and heterosexual men.

Approximately 800, 000 men in the United States are HIV positive, and innovative therapies have dramatically improved survival. Prostate cancer is a common malignancy in HIV-positive men. With improved therapies for HIV and increasing survival, the importance for screening and treating prostate cancer is increasing.

In a 2004 paper, Dr. Crum and her colleagues concluded that HIV-positive men aged 60-70 years had a higher rate of cancer diagnosis compared to an age-matched US general population rate. Dr. Hessol and her colleagues recently found that a cohort of HIV positive men in San Francisco had a significantly higher incidence of prostate cancer than the general population. In New York City, at the February 11, 2009 Gay Men and Prostate Cancer forum sponsored by the American Cancer Society, 50% of the audience self disclosed that they were both HIV positive and diagnosed with prostate cancer.

Many HIV positive men are receiving testosterone replacement and are not adequately being screened. If HIV truly does represent a risk for prostate cancer, then more rigorous screening may be necessary among men who have sex with men as a whole, and especially in those on testosterone replacement therapy. We ask the Committee that all funding for prostate cancer research include stipulations that men who have sex with men be identified and considered as a unique and significant cohort.

We thank the Committee for its leadership and for providing the opportunity to present four critical issues in prostate cancer regarding men diagnosed in their thirties and forties, African American men, Gay men and men presenting with late stage disease.

Presented by

Darryl Mitteldorf, LCSW

Executive Director

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