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Prostate Health Education Network, Inc.

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

Written Testimony Of
**Thomas A. Farrington, Prostate Cancer Survivor, and
President, Prostate Health Education Network, Inc.**

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PART I

House Committee on Oversight and Government Reform
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Statement of
**Thomas A. Farrington, Prostate Cancer Survivor, and
President, Prostate Health Education Network, Inc.**

Chairman Towns and members of the House Committee on Oversight and Government Reform, I am honored to appear before you today to address our nation’s prostate cancer crisis as a ten year prostate cancer survivor, and having witnessed the deaths of my father and both grandfathers from this killer disease.

Since my treatment for prostate cancer in 2000 I have worked nonstop to help educate others about this disease including founding the Prostate Health Education Network (PHEN) in 2003, with a focus on African American men who have the highest risk for being diagnosed with and dying from prostate cancer.

There is an urgent need for clarity in the fight against prostate cancer today. The high visibility debate sparked by the PLCO screening study released last year has caused public confusion elevating the risk of men most vulnerable to the disease. This confusion comes at a time when we have witnessed a steady decline in the prostate cancer death rates over the past decade which most attribute to earlier detection of the disease through PSA screening.

These are some of PHEN’s positions, concerns and recommendations for the committee:

- The PLCO study included approximately 10% of men at high risk for prostate cancer which would be analogous to a study on lung cancer which includes only 10% of smokers. Because of this and other factors in the conduct of the study we do not believe that the results should be the definitive basis for national policies on prostate cancer but important data to be included with what is already known.
- We strongly support early detection, and just as strongly disagree with any policies that would advocate men gamble with their prostates, and their lives, by not monitoring and knowing their prostate health through the use of the available tools. Today those tools include screening via the PSA test and digital rectal examination.

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- The federal budget for prostate cancer is inadequate to meet the education and awareness outreach needs, and the research needed for new detection and testing procedures that are mandatory to move us beyond today's confusion. We recommend that the budget be equivalent to that for breast cancer, a disease with comparable incident and death rates for women.
- Lack of access to treatment and lack of equal treatment where there is access, are critical factors in the higher African American death rate that need to be addressed.
- Expanded educational efforts for the public, and for doctors, should be undertaken to address the problem of over-treatment of prostate cancer.
- Prostate cancer is a medical, political and economic issue. We are concerned that the short term political and economic factors not be allowed to overwhelm and minimize the pressing medical needs.

Prostate cancer can be beaten, and it is also a disease that can end in tragedy which can often times be prevented. My personal and family experiences illustrate this.

In 2000 I was treated for prostate cancer after detection through regular PSA testing. Every six months since my treatment I would get a PSA test and in 2009 I had a disease recurrence. However, because of the early detection of this recurrence and my knowledge about treatment options I am free of prostate cancer in 2010. I have been blessed with no side effects from any of my treatments because of early detection and knowledge. Ironically, because of today's confusion about screening, some survivors no longer believe they should be screened after treatment, a major step backwards increasing the risk to those men who should be most on guard.

While battling my recurrence last year I lost two additional members of my family to prostate cancer. One, my age, did not get annual PSA testing. The other, my uncle, because of his age was told by his doctor that he would die of something else before prostate cancer. They both suffered horribly and needlessly. I also had another uncle diagnosed and treated successfully for the disease during this time. Unfortunately, my family situation is not unique but represents the real and chaotic multi-generational prostate cancer devastation within high risk families across our country today.

Black America is suffering a prostate cancer epidemic where men die at a rate 2.5 times higher than for all other men. At what stage the disease is detected, and with what knowledge, determine whether we live or die, and if we live whether we have a good or poor quality of life. However some of the policies now being advocated would accept this epidemic within Black America as "collateral damage."

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Chairman Towns and members of the committee, I sincerely thank you for addressing the prostate cancer crisis. We recommend that the policies and solutions for this significant health issue have a primary focus on those most in need and implemented with a sense of urgency, an approach taken with most other diseases of this magnitude. This is an approach that we believe will better serve all men. With a publicly clear well focused war on prostate cancer, and a high level of leadership and priority within the federal government, our nation can save countless lives, dramatically reduce suffering, and the overall economic impact of the disease.

I sincerely thank the committee for the opportunity to provide this statement.

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PART II

Written Testimony of
**Thomas A. Farrington, Prostate Cancer Survivor, and
President, Prostate Health Education Network, Inc.**

The Prostate Health Education Network, Inc., (PHEN) is a non-profit 501(c)3 organization. PHEN was founded in 2003 by Thomas A. Farrington, a prostate cancer survivor and author of the books, "Battling the Killer Within", and "Battling The Killer Within And Winning". PHEN is governed by a board of directors, and works with local advisory boards, partners and volunteers to assist with implementation of its programs and activities around the United States.

PHEN's primary mission is to increase prostate health education and awareness among African Americans. Saving lives through early detection and eliminating the African American prostate cancer disparity is PHEN's education and awareness goal. PHEN's mission also includes efforts to increase the overall support and resources to wage a war on prostate cancer that will eventually lead to a cure for the disease.

In 2005 PHEN organized and hosted the first ever "African American Prostate Cancer Disparity Summit." This historic event was held in collaboration with U. S. Senator John Kerry (MA) and U. S. Congressman Gregory Meeks (NY), and hosted in the Rayburn House Office Building. This summit is now an annual two day event which assembles members of congress, medical and research leaders, prostate cancer survivors and advocates to collectively address the prostate cancer epidemic. In 2009, for the second consecutive year, the summit was an official session of the United States Congressional Black Caucus' "Annual Legislative Conference." One day of the summit is now hosted in the Washington, DC Convention Center.

Why The African American Prostate Cancer Disparity? – This was a session held as part of the second annual summit in 2006. The presentations and findings are very pertinent to the hearing topic:

"Prostate Cancer: New Questions About Screening and Treatment"

Presenting as part of this session:

1. James L. Mohler, MD – Roswell Park Cancer Institute
2. Matthew Freedman, MD – Dana-Farber Cancer Institute
3. V. Diane Woods, Dr.P.H., M.S.N., R.N. – Loma Linda University
4. Timothy Gilligan, MD – Cleveland Clinic
5. Issac J. Powell, MD – Karmanos Cancer Institute
6. Mr. Yussif Dokurugu – Florida A&M University

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Each of the presenters outlined key findings resulting from their research projects that were related to better understanding the key factors causing the African American prostate cancer disparity. Some of the findings included:

1. There is a lack of communication between doctors and black men about screening and early detection. More than half the doctors in one government funded study did not discuss early detection with their patients and more than half the patients did not know why they should be screened.
2. A prostate cancer risk locus has been identified through genetic research that appears to be a stronger effect at an earlier age for African American men.
3. Evidence suggests that prostate cancer incidence is higher in African men than African Americans
4. African American men are less likely to be screened for prostate cancer, be treated aggressively for localized disease, be followed for PSA relapse after treatment, receive androgen deprivation therapy for advanced disease.

Each of the presentations are available on PHEN 's website at <http://prostatehealthed.org/page.php?id=66> in addition the presentations are available as part of PHEN Television at http://www.prostatehealthed.org/phen_tv_video.php?tv_id=3

In addition to these presentations other research has established that African American men are detected for prostate cancer at a later stage than white men. It has also been established that when black men and white men are diagnosed with the same conditions (stage and Gleason score) and receive the same treatment then the outcomes are the same.

The 2009 PHEN “African American Disparity Summit” addressed the subject:

Prostate Cancer Screening for African American Men

The Prostate cancer screening trial results released by the PLCO (Prostate, Lung, Colorectal and Ovarian) project team in March 2009 propelled this issue into the forefront of public visibility prompting debates on whether men should be regularly screened for prostate cancer. This session will presented an overview of the African American prostate cancer crisis, examined the screening debate issues as they relate to Addressing this crisis, and outlined a recommended set of early detection screening guidelines.

Session Moderator:

J. JACQUES CARTER, MD, MPH, Assistant Professor of Medicine, Harvard Medical School, PHEN Medical Advisor

Presentations:

The PLCO Prostate Cancer Screening Trial Results:

Christine D. Berg, MD - Chief, Early Detection Research Group, Division of Cancer Prevention, National Institutes of Health

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The National Comprehensive Cancer Centers (NCCN)

Position on Screening and Recommended Guidelines:

Mark Kawachi, MD -Chair of the NCCN Guidelines for Prostate Early Detection and Associate Professor of Surgery, Urology and Urologic Oncology at City of Hope Comprehensive Cancer Center

The American Cancer Society Position on Screening And Recommended Guidelines:

Durado D. Brooks, MD, MPH - Director of Prostate and Colorectal Cancers, American Cancer Society

The American Urological Association Position on Screening and Recommended guidelines:

Willie Underwood, III, MD, MS, MPH - Roswell Park Cancer Institute

The Impact on Public Policies:

Mr. Scott Williams, VP - Men's Health Network

All of the presenters support early detection screening for prostate cancer for African American men. The presentations are available on PHEN's website at <http://prostatehealthed.org/page.php?id=83> and they can be viewed on PHEN television at http://www.prostatehealthed.org/phen_tv_video.php?tv_id=26

PHEN's position and recommendation to the committee on the screening and treatment issues are that we use the knowledge that has been accumulated over the past years and increase the focus on the African American epidemic with the urgency and resources required to tackle a true epidemic which it is. This added urgency will surely accelerated new developments to aid in the overall prostate cancer crisis which will be available to assist all men. Efforts to minimize screening and early detection efforts because of the flawed PLCO study will be an acceptance of the African American epidemic. This would be a tragic direction in the fight against prostate cancer and one totally unacceptable to Black America.

Knowledge is the key prevention of prostate cancer deaths. PHEN has developed a national education and awareness initiative which is outlined here. Knowledge is an important part of treatment for prostate cancer. PHEN recommends that an audit assessment of the resources that are being allocated to prostate cancer education and awareness relative to the overall needs be made, again with a focus on the needs of the men most at risk and impacted by the disease.

PHEN's Rally Against Prostate Cancer - The PHEN "Rally Against Prostate Cancer" (RAP Cancer) initiative combines the outreach leadership efforts of prostate cancer survivors, cancer center partners, the communications reach of the internet, radio and television broadcasts for a broad and highly visible national movements to address the African America prostate cancer crisis. With an incidence rate 60% higher and a mortality rate 140% higher than for all other men

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in the United States, black men are in desperate need of help in the struggle against prostate cancer. Dramatically increasing the knowledge, awareness and support among these men at highest risk are the objectives of RAP Cancer

RAP Cancer Activities

The PHEN Survivor Network: PHEN mobilizes prostate cancer survivors to work together and assume leadership roles in the fight against prostate cancer within their communities. PHEN empowers the survivor network members with online tools, materials, PHEN TV programs, and other resources which leverage their valuable volunteer efforts to reach men where they are; in their homes, at work, church, and other organizations.

PHEN Web Portal (www.prostatehealthed.org): The hub for communications and information for PHEN's online and local grassroots outreach efforts. The Web Portal highlights activities in the various focus cities providing news, information on screening locations and other important resources. The PHEN blog and online support community are hosted on this site.

PHENTV.com: Online television programs featuring national leaders, survivors, celebrities and medical specialists. These programs are produced by PHEN from presentations at its annual summit, meetings and guest interview discussions. PHENTV.com serves as an important online education and awareness resource for the public, and a tool to support the local outreach efforts of the PHEN survivor network members.

Community Television Outreach: PHENTV.com programs are broadcast on community television stations in cities nationwide. PHEN releases new programs monthly for regular broadcasts. These visible education and awareness programs allow PHEN to educate men and their families at home, as never before done.

Radio Broadcasts: Members of the US Congressional Black Caucus, and others, have recorded PHEN radio awareness messages which are broadcast on local radio stations across the country. These broadcasts reach their constituencies who are at high risk for prostate cancer. PHEN also broadcast special radio programs with members of its survivor network and medical specialists via its monthly radio program which broadcast in Boston on 106.1 FM and worldwide on the internet at www.TOUCHFM.org.

Student Outreach: PHEN recruits college students to use their computers as tools to view and discuss PHENTV.com programs with family members who are at risk, and possibly facing prostate cancer. This initiative will also inform and educate students about prostate health issues and related career opportunities that they can pursue.

On Father's Day 2009, PHEN implemented its inaugural "Father's Day Rally Against Prostate Cancer" in partnership with 33 churches in Massachusetts. This groundbreaking and highly successful effort is the model for a national rally on Father's Day 2010 where more than one thousand churches are expected to join in. The rally, which takes place within each church, will receive a high level of visibility through the media; radio, television, internet and print with a theme of "*Joining Hands in Prayer to Save Lives.*"

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PART III

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

Accelerate Progress

www.accelerateprogress.org

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.prostatecancerfoundation.org

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Prostate Cancer International

www.pcainternational.org

Prostate Conditions Education Council

www.prostateconditions.org

Prostate Health Education Network

www.prostatehealthed.org

Prostate Net

www.prostatenet.org

Us TOO International Prostate Cancer Education and Support Network

www.ustoo.org

Women Against Prostate Cancer

www.womenagainstoprostatecancer.org

ZERO – The Project to End Prostate Cancer

www.zerocancer.org

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.

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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.

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- 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.