National Prostate Cancer Coalition

Working Together to End Prostate Cancer as a Serious Health Concern for Men and Their Families

1156 15th Street, N.W., Washington, DC 20005

Date: January 13, 1998

To: Melanne Verveer **Fax:** (202) 456-6244

From: Jay Hedlund **Phone:** (202) 463-9455
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Number of Pages: 5
(Including Cover Sheet)

This is for your perusal. Please feel free to contact me or my assistant, Brian Moran, if you would like additional information.

Thank you

Jen -

Melanne asked me to send this to you. Hum

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MEMORANDUM

January 12, 1998

To: **Chris Jennings**
Deputy Assistant to the President and Senior Health Policy Advisor
Domestic Policy Office

From: **Jay Hedlund**
President, National Prostate Cancer Coalition

Re: **Why Prostate Cancer Needs to be a National Health Priority**

As the President prepares his positions and remarks for the State of the Union address and his FY '99 Budget proposal, the following points on prostate cancer may be relevant regarding his views on increasing the federal commitment to bio-medical research.

- Prostate cancer is the most frequently diagnosed non-skin cancer in America and the second-leading cause of cancer death of American men (behind lung cancer). Prostate cancer represents more than 30 percent of all cancers in men.

- Prostate cancer accounts for approximately 20 percent of all new non-skin cancers, but receives less than 4 percent of federal cancer research funding.

- 209,000 men were diagnosed with prostate cancer in 1997 and 41,800 men died of the disease. About 20 percent of prostate cancers are now occurring in men between the ages of 40 and 60.

- Prostate cancer has a particularly devastating impact in the African-American community. African-American men have the highest prostate cancer incidence rates in the world. The mortality rate from prostate cancer for African-American men is more than twice that of white American men.

- In 1996, approximately the same number of lives were lost due to prostate cancer, breast cancer and AIDS. Deaths due to prostate cancer continued to rise in 1997. Deaths due to breast cancer and AIDS declined.

- In 1997, the federal commitment to breast cancer research was about 6 times that for prostate cancer research and for AIDS more than 16 times the allocation for prostate cancer.

- More money was spent to make the movie *Titanic* (more than $200 million) than spent by the federal government for prostate cancer research in 1997 (approximately $120 million).

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- Research works. In the 1950's when the country was shaken by the polio epidemic, research found a cure. In the 1980's the country made a national commitment to AIDS research – and that research has paid off in dramatic breakthroughs that have led to significant drops in AIDS deaths, improved quality of life and real prospects of a cure. While we need to continue the major commitment to AIDS research, we need that same kind of national commitment to research that will lead to cures for prostate cancer and breast cancer and other deadly diseases.

- Of special interest for Buddy, the First Dog: only two species in the animal kingdom have a prostate – humans and dogs. Dogs can develop prostate cancer if fed a heavy diet of food that humans consume.

CC: Ron Klain, Chief of Staff, Office of the Vice-President
Melanne Verveer, Chief of Staff, Office of the First Lady
Barbara Wooley, Public Liaison Office

By the Numbers

Prostate Cancer in America

209,000

The number of American men who were diagnosed with prostate cancer in 1997.

41,800

The number of American men who died of prostate cancer in 1997.

20%

The percentage of all non-skin cancer cases that are of the prostate.

3.6%

The percentage of all federal cancer research funding dedicated to prostate cancer research.

$250 million

The amount of promising prostate cancer research that was ***not*** conducted in 1997 due to lack of funding.

The National Prostate Cancer Coalition

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Testimonials of Prostate Cancer Survivors & Spouses

- **H. Norman Schwarzkopf, U.S. Army general, retired**
  "The PSA test is important, but by itself it is no enough (my number was 1.2, which led me to believe I didn't have cancer). The digital-rectal examination is absolutely necessary and the patient should challenge the doctor to take as much time as necessary for a thorough examination. Screening and early detection allowed me to undergo a complete cure, and today I am cancer-free."

- **Robert Dole, Former U.S. Senator**
  "If I have one message about prostate cancer it is this: There is no doubt that early detection and research save lives. So my advice to every man is to get tested regularly and voice your support of increased funding for prostate cancer research."

- **Richard Shelby, U.S. Senator**
  "Prostate cancer is a disease that has a similar incidence and death rate to breast cancer yet receives one-fourth as much research money. This is a serious oversight that we should correct to increase the pace of research and develop conclusive evidence on what really works and does not work in treating prostate cancer."

- **Ted Stevens, U.S. Senator**
  "An annual prostate checkup meant much for me. My physician found signs of change in my prostate during my yearly visit in 1990. After follow-up tests, the diagnosis was cancer – before it had spread. Surgery took care of my problem; annual exams continue to confirm complete recovery."

- **Jesse Helms, U.S. Senator**
  "The dangerous reality of prostate cancer has struck a number of us here on Capital Hill. Fortunately for me, surgery was not necessary – I underwent radiation therapy every morning for 39 days. It goes without saying that I am thankful for early detection and am convinced that it was the key to my recovered health."

- **Rep. James A. Leach, U.S. Congressman**
  "I encourage all people reading this to contact your representatives. A little phone call could make the difference in prostate cancer funding. If we can increase research dollars then I believe we can get that much closer to finding a cure."

- **Betty Gallo, wife of the late Dean Gallo, retired U.S. Congressman. Board member of NPCC.**
  - *"On Feb. 10, 1992, my whole life changed. Dean informed me that he had prostate cancer and that his PSA was over 800. When he told me this, the first thing I did was pray.*
  - *"In August 1994, while fighting prostate cancer, Dean decided to retire from Congress. He was in tremendous pain."*
  - *"President Bush came to New Jersey for an event honoring Dean's retirement from Congress. Unfortunately, Dean could not attend. The President came to the hospital and saw Dean before the event."*
  - *"A few days later, Dean passed away, and the last thing Dean said was, Jesus, please take me now."*
  - *"Dean and I fought prostate cancer with faith and love, and now I am a dedicated, active participant in the fight against prostate cancer."*

- **Robert J. Samuels, retired banker. Chairman of the National Prostate Cancer Coalition.**
  - *"In October 1994, a urologist friend of mine ordered a series of tests for me because of my high PSA level. While lying on the doctor's table, results to my second biopsy came back within 20 minutes indicating positive."*
  - *"My initial reaction was shock, confusion, fear, anger, depression, self pity"*
  - *"I realized that this disease would not only affect me, but all the people who love and care about me."*
  - *"There needs to be more federal research funding for prostate cancer, and we need to target and build awareness with the African American community."*

Call Sarah

Sarah A. Bianchi 09/23/97 09:28:36 PM

Record Type: Record

To: Jennifer L. Klein/OPD/EOP

cc:
Subject: prostate cancer

I keep meaning to write you a thorough memo on prostate cancer but more information keeps coming up, so I thought I would give you a brief (this did not turn out too brief) update of what I have learned so far.

Prostate cancer is the most commonly diagnosed cancer in the United States (334,550 this year) and second only to lung cancer in terms of deaths (41,800). It is even more common among African-American men.

We know that if prostate cancer is detected early, survival rates are often much higher. 100 percent when localized, 94 percent with regional disease. Thirty-one percent when it has metastisized. However, there are still not recommendations that screening is the best answer. The head of prostate cancer at NIH tells me that there are essentially two kinds of prostate cancer -- one which spreads and kills you and another where tumors stay dormant for years. Unfortunately, current screening tests cannot distinguish between the two. There are many side effects of surgery -- impotency, and other possible health risks and there are various recommendations from the American Cancer Society, NIH, and CDC about whether screening is advisable. (There is a new Medicare benefit that covers prostate cancer but does not go into effect until the year 2000 -- I think in part b/c they do not quite know how best to implement given the science.)

However, there is a conference in Houston in December with NIH, CDC, and the American Cancer Society where -- for the first time ever -- they are going to make a consistent recommendation that prostate cancer screening should be an indiviidual decision. They are stating that doctors, providers, etc should make clear the pros and cons and help individuals make the best decision. This conference focuses primarily on prostate cancer in African-Americans. They would, of course, love any high profile attention or attendance to this conference or anything we could do to amplify their message.

Helping more people participate in clinical trials. A second possible opportunity is that there apparently is a big shortage of people participating in clinical research trials for prostate cancer -- and cancer in general. Another kind of public message we may want to consider is a way to encourage more people to participate in screening -- whether through a high profile meeting, event or other outreach activities. This is particularly important in prostate cancer where unlike say breast cancer we do not even have the research to make early detection recommended.

I am interested in this issue of lack of participation in clinical trials in general. There are big concerns about private plans often not covering this. While I know we are not in the practice of mandating benefits, this is a bit different because for NIH trials and most other trials the researchers foot the bill for the medicine -- insurers are just asked to foot the bill for extra care involved. (I am tracking down exactly what this means). Apparently, NIH has some deal with VA and CHAMPUS on this and there is a Rockefeller bill that proposes to have Medicare cover it (not yet scored). The Quality Commission also plans to address this issue and recommend that plans

cover it. Anyways, I am learning more but I think this is a potentially good area where we could make a big difference in research efforts maybe without big dollars -- maybe even as part of this millenium thing the First Lady mentioned in recent cancer article you forwarded.

Other Cancer Ideas. In my inquiries about prostate cancer, I did learn some options for other cancer initiatives. One is skin cancer. The main emphasis with skin cancer is education and prevention. Most people -- including yours truly -- are not taking the necessary and recommended precautions. Most Americans get the vast majority of their exposure to the sun before they turn eighteen (I knew there was a health benefit of this job) -- so there needs to be more kids/school-based outreach. One time we can highlight this is in the spring when the CDC is releasing their guidelines for skin cancer education in school-based programs. But there could be other possibilities sooner if we want.

Colorectal Cancer. Unlike prostate cancer, it is generally agreed that we do have the science with colorectal cancer so that screening and early detection can save lives. We just passed a colorectal benefit in Medicare, but we do not have any kind of public health initiative like the CDC breast and cervical screening program which provides screening to low-income people etc). There is potential here for an initiative as well -- at least some kind of education/outreach initiative and if we want to put money into this than CDC could start a similar program for colorectal screening that they have for breast cancer. They say that -- to some extend -- they could build off the infrastructure that is set up for the breast cancer program. They are getting me cost estimates but any initiative would enable us to say we started the first big public health screening program on colorectal cancer.

I will get back to you as I learn more. I am looking into prostate cancer info you sent today as well as other stuff. There was also a big hearing on this on the Hill today as well (Bob Dole testified). But let me know what you think sounds promising.