



# National Prostate Cancer Coalition

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

202  
232  
7608

# Fax

**To:** Donna Geisbert **From:** Flo McAfee

---

**Fax:** 202-456-7431 **Pages:** 2 including cover

---

**Phone:** 202-456-5594 **Date:** 02/26/98

---

**Re:** NPCC Leadership Training Session **CC:** Jay Hedlund, President, NPCC

---

Urgent  For Review  Please Comment  Please Reply  Please Recycle

• **Message:**

Here are additional details regarding the National Prostate Cancer Coalition (NPCC) legislative session on Monday, March 2. This session is part of a 2-day leadership training session and lobby day conducted by NPCC. Approximately 70 people will be attending including prostate cancer survivors, NPCC board members and advocates. The Legislative Session will run from 9:30 am to 10:15 am. The other speaker will be either Congressman Billirakis or a member of his staff. Each speaker will have 10 to 15 minutes to speak followed by 10 minutes of questions from the audience. Tom Bruckman, NPCC's policy chair and the executive director of the American Foundation for Urologic Disease (AFUD), will moderate the session and introduce the speakers.

It would be most helpful if Chris gave an overview of the Administration's initiative on cancer research and provide any specifics on prostate cancer.

Attached is a copy of the Monday agenda to give Chris an idea of the other activities taking place. On Tuesday, the group has Hill meetings. They want to encourage members of Congress to increase spending for prostate cancer research. NPCC is encouraged by the President's cancer initiative and hopes that more money can be directed toward research on prostate cancer.

The session will take place at the following:

**Location:** Doubletree Hotel, 1515 Rhode Island Avenue, NW (Note: This is two blocks up from the Washington Post and Madison Hotel on 15<sup>th</sup> Street.)

**Room:** Terrace West Ballroom (located on the main floor of the hotel)

**Time:** 9:30 am to 10:15 am

I will be willing to meet Chris at the entrance of the hotel around 9:25. If you need additional information, please give me a call at (202) 463-9455 or over the weekend at P6/b(6)

Thanks.

**National Prostate Cancer Coalition  
Leadership Training and Congressional Strategy Session  
Monday, March 2, Washington, DC  
Doubletree Hotel, 1515 Rhode Island Avenue, NW**

*Tentative Agenda 2/10/98*

- 9:00-9:30            Welcome/Introductions  
                      Overview of the Agenda  
                      Jay Hedlund, President, NPCC
- 9:30-10:15        Perspectives on Legislative Environment
- Tom Bruckman, Policy Chair, NPCC
  - Chris Jennings (invited), White House
  - Congressional Staffer
- 10:15-10:30        Break
- 10:30-11:45        Lobbying Techniques  
                      Q & A  
                      Vin Weber, Clark & Weinstock
- 12:00-1:15        Lunch  
                      Introduction, Bob Samuels, NPCC Chair  
                      Speaker, Col. Irene Rich
- 1:30-3:00        Grassroots Lobbying Techniques or Media Training Skills\*
- 3:00-3:30        Break
- 3:30-5:00        Grassroots Lobbying Techniques or Media Training Skills\*
- Dinner            On your own

*Optional Evening Activity: Basketball Game, Washington Wizards v. LA Lakers, 7pm  
(Each seat costs \$35. A limited number of tickets are available. Call 202-223-9541 x116  
to reserve tickets.)*

*\*For the afternoon, the full group will be split into 2 smaller groups for interactive  
training. Each of these sessions will be offered twice and will cover the same  
information.*



Chris

Just in case you don't read  
your 3-maw - hope you  
can do this - remember  
all those blessings by your  
local volunteer Paulsen

XXOO  
Your Local Volunteer!



# National Prostate Cancer Coalition

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

---

February 5, 1998

Chris Jennings  
Deputy Assistant to the President and  
Senior Health Policy Advisor  
Domestic Policy Office  
The White House  
1600 Pennsylvania Avenue, NW  
Washington, DC 20500

Dear Mr. Jennings:

The National Prostate Cancer Coalition is encouraged by the cancer research initiative outlined recently by President Clinton and Vice President Gore. We believe this important initiative can accelerate momentum toward meaningful breakthroughs.

We believe that prostate cancer, which has lagged as a cancer research priority in the past, can benefit greatly by this enhanced federal commitment to cancer research. That will only happen, however, if the public, Congress and the Administration put new attention on the need for prostate cancer research. As you know, while prostate cancer constitutes 20 percent of all new non-skin cancer cases, less than 4 percent of federal cancer research and awareness funds currently go to prostate cancer.

We look forward to working with you and others in the Administration to ensure equity for prostate cancer research as the nation goes forward with its major cancer research initiative.

**Toward that end, the National Prostate Cancer Coalition would like to invite you, as part of a panel, to address a group of prostate cancer grassroots activists on Monday, March 2, 1998 at noon at the Doubletree Hotel, 16<sup>th</sup> Street and Rhode Island Avenue (Scott Circle). The panel will include a senior staff aide from Capitol Hill and a representative from the Department of Defense congressionally mandated prostate cancer research program.**

The audience of about 75 people will include the Board of Directors of the National Prostate Cancer Coalition, representatives of other national groups working on prostate cancer advocacy and about 50 activists from around the country who will be in Washington for briefings, training and lobbying on prostate cancer issues.

Attendees would benefit greatly from hearing your views on the new cancer research initiative and how they and the NPCC can work with the Administration to

ensure that the necessary funds are appropriated by the Congress to make the goals of that plan a reality. We hope that you can join us.

We will be in touch with your office to see if arrangements can be made for you to participate in this important briefing.

Sincerely,

Jay Hedlund  
President and CEO

Jay ~~PHO~~ Hedlund  
P.A.H.

Tam

### The Problem.

- This year over 210,000 men are expected to be diagnosed with prostate cancer and over 42,000 men are projected to die from this disease (virtually the same number of women who die from breast cancer). Only lung cancer claims more cancer deaths for men.
- Prostate cancer does not manifest itself in most men until they have reached traditional retirement age and, when it does, there are great disparities among minorities relative to incidence.
- In fact, fully 80 percent of those diagnosed with this disease are over age 65. African American men have an incidence rate over 35 percent higher than white men. Interestingly, Asian-Americans have an incidence rate that is less than half of white Americans. (Clinical trials are underway at NIH to determine the causes of these differences.)

### Administration Agenda.

- **Medicare Cancer Clinical Trials.** This policy is particularly important for people with prostate cancer b/c:
  - (1) Lack of participation in prostate clinical trials is a bog problem -- some trials have been shut down.
  - (2) Most people get prostate cancer after 65 -- when eligible for Medicare.
- **Cancer Research Funding.** The President's budget includes a 10 percent increase in cancer research funding and 65 percent over five years.

→ Race & Health - included \$ for awareness

→ DoD - \$45 million

→ Medicare Screening for prostate cancer implementation 2000

→ Prostate cancer progress review group  
- (9 month review process to identify new research opportunities)

→ Cancer Genome Anatomy Group

## PROSTATE CANCER

### BACKGROUND:

210,000 men are predicted to be diagnosed with prostate cancer this year, making it the most common non-skin cancer in American men. It is only the second leading cause of cancer death for men (a second distant behind lung cancer) About 42,000 deaths are expected this year.

(Comparatively about 180,000 women will be diagnosed with breast cancer this year and about 44,000 will die).

Eighty percent of the men diagnosed with prostate cancer are over the age of 65. African-American men have an incidence rate about 37 percent higher than white men. In addition, their mortality rate is twice as high of that of whites. Asian-Americans have the lowest rate of prostate cancer.

### BUDGET:

In FY 1998, NCI will spend about \$84 million on prostate cancer, an 248% increase since FY 1993. Breast cancer spending at NCI has increased 160% over this same time period. However, the overall spending on breast cancer research at the NIH is much higher (\$338.9 million in the President's 1998 budget).

### SUMMARY OF RESEARCH:

There are currently nearly 60 clinical trials being conducted on prostate cancer. Studies are currently being done to understand why some races are more prone to prostate cancer. It is believed that these studies will lend a great deal of insight into the nature of this disease. There are also studies on the environmental, dietary, occupational and genetic (see section on genetic research) on prostate cancer. The study that is furthest along is a clinical prevention trial involving 18,000 healthy men over age 55 to determine if the drug finasteride can safely reduce the risk of developing this cancer. This study also seeks to help better define who is at risk for prostate cancer, and improve early detection and screening technologies.

There are also studies being conducted that seek to improve treatment for prostate cancer, including an emphasis on reducing the side effects of treatment (usually impotence and in older patients sometimes death). There has been some recent progress in the treatment of prostate cancer, including a recent discovery that hormone therapy after radiation therapy can prolong disease free survival and overall survival of patients with locally advanced prostate cancer.

## **SCREENING RECOMMENDATIONS:**

The PSA test for prostate cancer measures the level of prostate specific antigen (PSA) in blood. It detects early stage tumors. However, it can lead to some men receiving aggressive treatment for abnormalities found in the screening that do not need to be treated. There is also a possibility that prostate tumors may remain latent for a number of years. There is currently no ways to predict accurately which cancers will progress rapidly. The uncertainties that remain about which men will benefit from treatment obviously complicates the issue of whether to screen asymptomatic men for the disease. Given the existing level of knowledge, there are no recommendations on whether the men should screen.

The American Cancer Society, CDC, and NIH are working to develop guidelines about prostate cancer. (FYI -- in a conference in Houston in December -- for the first time ever -- these three organizations are going to make a consistent recommendation that prostate cancer screening should be an individual decision. They will recommend that doctors and other health care providers should make clear the pros and cons of screening. The primary focus of this conference is prostate cancer in African-Americans.)

NCI is carrying out the Prostate, Lung, Colorectal, Ovarian Cancer Screening Trial -- one of the largest clinical trials in history with 185,000 participants -- to assess the efficacy of screening for prostate cancer and other cancers. Recent sites have been added to encourage participation of minorities.

## **GENETICS:**

In a recent study of Ashkenazi Jews in the Washington, D.C. area that found three specific alterations in breast cancer genes BRCA1 and BRCA2 also assessed prostate cancer risk for men carrying BRCA1 or BRCA2 alterations. Scientists estimate that men with one of the alterations have a 16 percent chance of getting prostate cancer by age 70, compared to 3.8 percent for non-gene carriers. In a separate study, scientists narrowed down the location for the first prostate cancer gene HPC1. It is estimated that one in 500 men carry an altered version of HPC1. The gene once identified is expected to provide insight into the cause and progression of both the hereditary and sporadic forms of prostate cancer.

## **CANCER GENOME ANATOMY PROJECT:**

NCI has begun the Cancer Genome Anatomy Project the goals of which are to build an infrastructure of resources, information, and technology to establish an index of all genes that are expressed in tumors and to support the development of new technologies to better understand these genes. The tumor type with the highest representation in the early stages of the CGAP effort is prostate cancer.

## **PROSTATE CANCER PROGRESS REVIEW GROUP:**

This group started in June is conducting a nine-month review to assess research opportunities in prostate cancer. It will also assess the activities of NCI in the context of these opportunities and help set NCI's research agenda in prostate cancer by identifying and prioritizing those scientific opportunities.

## **DEPARTMENT OF DEFENSE:**

DoD was authorized to spend about \$45 million on prostate cancer research in FY 1997. This is the first time that DoD has been given money to spend on prostate cancer research. However, for the past five/six years they have been given money to spend on breast cancer research. This year \$112 million has been authorized for this program. This program has been applauded by the cancer community and the Institute of Medicine recently wrote a report praising it. It is particularly popular because it involves breast cancer survivors and advocates on the panel that determines grants. DoD is planning to announce the first grants in the next few months. (Also FYI -- remember Jen K asked why we do not propose dollars for these programs in our budget. I talked to DoD about this and they told me that they never ask for this spending because not within their overall mission).

## VICE PRESIDENT GORE ANNOUNCES HISTORIC CANCER INITIATIVE

January 29, 1998

*"We've won a great many battles, but we know we can't stop until we win the war. That is why, even as we are balancing the budget and making tough cuts across the board, we must invest more in the war against cancer. We must give America's families new hope for a healthy future."*

-- Vice President Gore, January 29, 1998

Today, Vice President Gore announced a historic initiative to step up the battle against cancer. Building on the Administration's support for legislation to prevent genetic discrimination by health insurers and employers, the President's new cancer initiative includes:

- *A historic \$4.7 billion increase in spending in cancer research at the National Institutes of Health (NIH), a 65% increase over the next five years; and*
- *A groundbreaking initiative that explicitly provides coverage of cancer clinical trials for Medicare beneficiaries.*

*More than 40 percent of Americans will be diagnosed with cancer during their lifetime and more than 20 percent will die from it.* While scientists have made important strides in cancer, particularly in childhood cancers, experts believe that we are at the cusp of important new breakthroughs in the war against cancer that merit or justify a much greater investment in research that could lead to help better diagnose, prevent, treat, and potentially cure cancer.

*Less than three percent of cancer patients participate in clinical trials. Americans over the age of 65 make up half of all cancer patients, and are 10 times more likely to get cancer than younger Americans.* Many scientists believe that higher participation in clinical trials could lead to faster development of therapies for more of those in need, as it often takes between 3 and 5 years to enroll enough participants in a cancer clinical trial to make the results scientifically legitimate and statistically meaningful. Furthermore, older Americans frequently cannot participate in cutting edge cancer clinical trials because Medicare does not pay for such treatments until they are established as standard therapies.

**Historic Increases in Cancer Research at the National Institutes of Health.** The Vice President announced a 65 percent increase in funding for cancer research at the NIH over the next five years. This is part of the President's proposal for an unprecedented \$1.15 billion increase at the NIH in FY1999 and a nearly 50 percent increase over the next five years.

- **Unprecedented new investment of \$4.7 billion in cancer research over five years.** In 1999 alone, the Administration is proposing a 10 percent increase in cancer research and by 2003, the NIH will spend \$4.8 billion on cancer research. A significant and new increase in research has great potential to improve early detection and diagnoses of cancer; speed the discovery and development of new cancer drugs and devices; dramatically increase adult participation in clinical trials; and provide all cancer patients and their care givers with easy access to the latest information on treating their disease.

- **Investment will support cancer research throughout the NIH.** Almost 90 percent of the cancer research money will be supported at the National Cancer Institute, but the initiative will also involve new and enhanced activities in at least twelve other Institutes of the NIH, such as the Human Genome Project.

**Coverage of Cancer Clinical Trials for Medicare Beneficiaries.** The Vice President also announced that, for the first time, Medicare beneficiaries would be able to have the patient care costs associated with cancer clinical trials explicitly covered through a new demonstration. This would give Medicare beneficiaries access to cutting-edge treatments and encourage higher participation in clinical trials.

- **Gives Medicare beneficiaries access to cancer clinical trials.** The Administration's proposal would establish a three-year demonstration program for Medicare beneficiaries, to cover the patient care costs for those who participate in certain federally-sponsored cancer clinical trials. The proposal is based on NIH-sponsored clinical trials but will allow for determination of the eligibility of an alternative set of trials by the Secretary of Health and Human Services within the same funding constraints, with the advice of the Institute of Medicine's National Cancer Policy Board. The President's budget would establish a three-year demonstration program, specifically for Medicare beneficiaries, to cover the patient care costs for those who participate in cancer clinical trials.
- **Administered through HCFA for Medicare beneficiaries, but has no impact on the Medicare Trust Fund.** The demonstration would be administered by the Health Care Financing Administration, which administers Medicare, but would be funded by \$750 million in receipts from tobacco legislation. It would therefore have no effect the financial condition on the Medicare Trust Fund. The proposal includes a review and evaluation of the demonstration by the Secretary of Health and Human Services, in consultation with the Institute of Medicine's National Cancer Policy Board, to consider whether to extend and/or expand the demonstration, no later than 30 months after enactment.
- **Builds on the bipartisan legislation in the Congress.** Senator Mack and Senator Rockefeller and Representative Nancy Johnson have taken leadership in this area by proposing similar legislation that would provide cancer clinical trial coverage for Medicare beneficiaries. The Administration looks forward to working closely with these leaders, as well as other Members of Congress, on this important issue.

Crossword 9D  
 Editorial/Opinion 14-15A  
 Lotteries 9D  
 Marketplace Today 7D  
 State-by-state 12A  
 Stocks 6-9B

The Federal Communications Commission is cracking down on long-distance companies that gouge consumers at pay phones and hotel-room phones by making it easier to find out the rate before calling.

It is expected to approve rules today that will require long-distance carriers to provide a recording telling callers

the posting of a phone number so callers can find out the cost. But that option is neither clear nor convenient, regulators say.

The new rules would apply to interstate credit-card, collect or other billed calls from the USA's 7 million pay phones, as well as phones in rooms at hotels, hospitals and schools.

Armed with knowledge,

man William Kennard says.

The exorbitant rates, which are legal, are generally charged by smaller companies that cut deals to pay high commissions to pay phone operators and owners of stores, hotels, bars and other locations.

Calls that might cost \$5 to \$10 using a major carrier like AT&T, MCI or Sprint could cost

heavy fees by dialing an 800 number or access code to reach their normal carrier.

Yet many mistakenly believe their carrier automatically handles the call as long as they use a calling card number, only to be shocked when they get their bills. The problem prompts about 4,000 complaints to the FCC each year.

about whether they saw thing while protecting GI that would support allegation that he had the affair.

Treasury officials fear forcing agents to break traditional code of silence would jeopardize the effectiveness of the presidential security.

William Ginsburg, the lawyer representing Lewinsky, said there is "an open line of communication" with the team as they try to clarify client's offer to testify in court for immunity.

Index to coverage, 3A

### Ex-intern watches president's speech

Monica Lewinsky, what millions of Americans did Tuesday night, watched President Clinton's State of the Union address.

"She thought he did good job," says her lawyer William Ginsburg, "but she thinks he's done a good as president." Story, 3A.

## Proposal: Seniors get access to new cancer drugs

By Steven Findlay  
 USA TODAY

Medicare will pay for some experimental cancer treatments for seniors under a plan announced today by Vice President Gore. The proposal also calls for a sharp increase in government funding for cancer research.

The administration's plan, a three-year pilot program, will cover seniors who agree to participate in clinical trials of experimental therapies, primarily new drugs. However, seniors

will initially be restricted to trials sponsored by the National Institutes of Health.

About 25% of all tests of new cancer treatments are sponsored by NIH. Administration officials said Wednesday they had no estimate of the number of seniors who would benefit.

"This is very good news for seniors who will be diagnosed with cancer," says Ellen Stoval,



Gore

of the National Coalition for Cancer Survivorship, an advocacy group. "But it is a limited program — only a first step."

Although half of new cancer cases each year occur among people age 65 or over, seniors have limited access to experimental treatments because Medicare pays only for approved treatments.

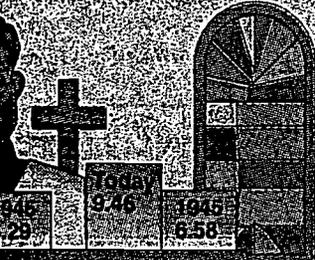
The program will cost an estimated \$750 million. Adminis-

tration officials said they would propose that it be funded from new taxes on tobacco or money from any settlement Congress would approve between states and the tobacco companies.

Gore will also announce that the administration will ask Congress to increase cancer research funding by 60% over the next five years, the largest increase since the early 1980s.

The government will spend about \$2.9 billion this year on research. The administration wants Congress to increase that to \$4.8 billion by 2003.

performs more funerals and burials in 1945, but fewer marriages today vs. 1945.

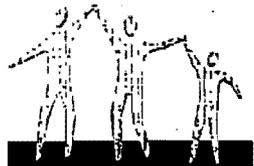


Funerals

By Anne R. Carey and Elys A. McLean, USA TODAY

FOR USA TODAY SUBSCRIPTION AND CUSTOMER SERVICE ... CALL 1-800-USA-0001

File "Vice President's cancer plan"



Friends of  
CANCER  
RESEARCH

An Organization  
Commemorating  
the 25th Anniversary  
of the National Cancer Act

File Vice President's  
**Press Release**

Cancer Event

Embargoed for release until 9:00AM EST, January 29, 1998

Contact: Missi Tessier (202) 393-1010

**FRIENDS OF CANCER RESEARCH HAILS  
ADMINISTRATION CANCER RESEARCH FUNDING INITIATIVE**

The Friends of Cancer Research today hailed President Clinton and Vice President Gore's proposal to increase cancer research funding for Fiscal Year 1999 as "a significant step forward in the fight to eliminate cancer." The President announced the initiative in his State of the Union address on Tuesday.

"Too many of us have watched those we love suffer and lose their lives prematurely to cancer. Right now, the main obstacle to new discoveries to end that suffering is money," Dr. Sigal said. "There are promising new therapies that aren't being tested because we simply don't have the resources. Four out of five approved research proposals go unfunded -- proposals that may contain the breakthroughs we need to make a difference. We salute the President and Vice President for making increased cancer research funding a top priority and look forward to working with them to make the proposal a reality."

"We also support the Administration's proposal to offer clinical trials to Medicare patients," Dr. Sigal said. "This pilot program will not only give hope to many cancer patients around the country, but it will help advance cancer research."

The Friends of Cancer Research is a non-profit organization formed to spearhead a public awareness campaign about the importance of cancer research. It has successfully reinforced that message with key policymakers and media both directly and in partnership with the Creative Community Task Force on Cancer.

SENT BY BASS & HOWES 1-20-98 11-20 BASS & HOWES 200 100 0000 1 1

NATIONAL BREAST CANCER COALITION

*\* a grassroots advocacy effort \**

**Statement of the  
National Breast Cancer Coalition  
in support of the  
President's Initiative to Establish a  
Medicare Cancer Clinical Trial Coverage Demonstration Project**

**January 29, 1998**

---

The National Breast Cancer Coalition (NBCC) applauds President Clinton and his Administration for their support of a Medicare Cancer Clinical Trial Coverage Demonstration Project and their continuing commitment to eradicating breast cancer.

The Clinton Administration's proposal is vitally important to every aspect of breast cancer - to making certain that we learn how to prevent the disease, cure it and best treat it and insuring that managed care and insurance companies make decisions on the highest quality scientific evidence and not just cost.

The Clinton Administration has steadfastly supported the goals and mission of the NBCC during the past five years. This Administration recognizes that breast cancer is not just an issue for one month, but an ongoing crisis. Their work has helped make finding the cause of and a cure for breast cancer a national priority by increasing research efforts and improving current breast cancer policy.

Today's announcement of the Medicare Cancer Clinical Trial Coverage Demonstration Project further establishes the Administration as the leader in the effort to create national policies which will lead to the eradication of breast cancer. Without clinical trials we simply will not move forward in our efforts to eradicate this disease. It is only through encouraging increased research and incorporating the use of evidence-based science and new technology in treating patients that we will be able to find the urgently needed answers about breast cancer.

The unparalleled contribution made by clinical trials to the progression of evidence and science based medicine and health care, clearly illustrates the need to provide insurance coverage for patients enrolled in clinical trials. The proposed demonstration project, which offers reimbursement for out of pocket expenses to Medicare patients, is the first critically needed step toward providing coverage to all clinical trial participants.

SENIOR DIRECTOR OF POLICY & PROGRAMS      1 20 00      11:20      DIRECTOR OF POLICY & PROGRAMS

Because we still do not know the cause or have a cure for breast cancer, the NBCC, a grassroots advocacy organization made up of over 400 organizations and hundreds of thousands of individuals, is dedicated to the eradication of breast cancer. The NBCC's goals are (1) to increase the federal funds available for research into breast cancer and to focus research on prevention, on finding the cause of and a cure for this insidious disease; (2) to make certain that all women have access to the quality care and treatment they need, regardless of their economic circumstances and (3) to increase the influence of women with breast cancer in the decision making that affects their lives. On behalf of the 2.6 million women living with breast cancer, with the ongoing exceptional commitment of President Clinton and support from our friends in Congress, the National Breast Cancer Coalition will continue to work to make this proposal reality.



## AMERICAN ASSOCIATION FOR CANCER RESEARCH, INC.

PUBLIC LEDGER BUILDING • SUITE 826  
150 SOUTH INDEPENDENCE MALL WEST  
PHILADELPHIA, PA 19106-3483  
TELEPHONE: (215) 440-9300 • FAX: (215) 440-9313

MARGARET FOTI, Ph.D.,  
EXECUTIVE DIRECTOR

Embargoed  
For Release: January 29, 1998

Contact: Jenny Anne Horst-Martz  
AACR  
(215) 440-9300  
E-mail: horst@aacr.org

### American Association for Cancer Research Salutes Presidential Initiative on Cancer

PHILADELPHIA -- The American Association for Cancer Research (AACR) today hailed President Clinton's announcement, made during the State of the Union Address on Tuesday, that he would seek a large increase in funding for the National Institutes of Health, and specifically the National Cancer Institute (NCI), to speed new developments in the battle against cancer.

AACR President Donald S. Coffey, Ph.D., had written to President Clinton and Vice President Gore in December to urge that the Administration propose a significant increase in funding for the NCI, and more than 30 other cancer organizations endorsed this request. "We are delighted about the new cancer research initiatives just announced by the Clinton Administration. Make no mistake about it, the commitment of President Clinton and Vice President Gore to cancer research will save thousands of lives, and we are deeply grateful to them for their leadership and vision," Dr. Coffey stated. "We look forward to working with the President, Vice President, and Members of Congress to ensure that these funds are realized in the FY 1999 budget."

-more-

Dr. Coffey noted that the Nation's past investment in cancer research has been meager as compared with the enormous cost of cancer. "The United States spends over \$100 billion each year to deal with the effects of cancer, but we have spent only a little more than \$2 billion annually to figure out how to prevent and cure this horrible illness," Coffey stated. He noted that cancer has a devastating effect on families, and thus the President's commitment to enhancing cancer research will be welcomed across the Nation. "This new initiative is an important first step toward providing the gravely needed resources to mount a 'real war on cancer' that will result in victory over this terrible disease."

Dr. Coffey emphasized that the eradication of cancer is within researchers' sights. "Research has already found the cure for several forms of cancer, including some childhood cancers that were once considered uniformly fatal. Expanding the research effort through additional funding will cure or prevent the remaining cancers," he stated.

Founded in 1907, the American Association for Cancer Research (AACR) is a professional society of more than 14,000 laboratory and clinical scientists engaged in cancer research in the United States, Canada, and more than 60 other countries. The AACR's principal activities include fostering advances in cancer and biomedical research through programs that promote scientific communication and science education and training, organizing scientific meetings for the presentation of new and significant discoveries in the cancer field, and publishing four major peer-reviewed scientific journals (*Cancer Research*, *Clinical Cancer Research*, *Cell Growth & Differentiation*, and *Cancer Epidemiology, Biomarkers & Prevention*).

###



January 29, 1998

The Honorable Albert Gore, Jr.  
Vice President of The United States  
The White House  
Washington, DC 20500

Dear Vice President Gore:

The American Cancer Society commends you for your leadership in bringing forward two critical cancer initiatives - a significant increase in cancer research funding, and a demonstration program covering patient care costs for those Medicare beneficiaries enrolled in NIH-sponsored cancer clinical trials. These initiatives represent an important step in our national efforts to mount a new attack on cancer through a revitalized National Cancer Program.

The proposal to increase funding for cancer research at the National Cancer Institute is a critical component of this effort. The American Cancer Society and others have called for this increased investment in order to move today's knowledge about cancer more rapidly to the next level of breakthroughs, exploiting in particular our understanding of molecular biology and genetics and to enhance clinical research efforts. An expanded cancer research initiative must also include continued study of individual and social behaviors to develop more effective cancer interventions and define information needs -- for the public and cancer survivors alike, and stepped up efforts to translate research findings into cancer fighting tools available to all Americans. We applaud this announcement, and support its intent, but call on the Administration and Congress to more broadly define our investment in cancer research so that we are fighting cancer on all fronts - not just in the laboratory.

The Society has long advocated for full coverage of all costs of participating in cancer clinical trials - often the best treatment option for those patients for whom standard therapies are not satisfactory. The proposed new Medicare demonstration project for coverage of clinical trials will ensure that more older Americans have access to a wider range of new and potentially effective treatment options. We commend the Administration's commitment to expanding the demonstration project to include other quality cancer clinical trials if recommended by the National Cancer Policy Board. The American Cancer Society believes that all Americans should have access to high quality cancer clinical trials, and have been working with Senators John Rockefeller and Connie Mack to enact legislation that would establish a broad benefit under Medicare for coverage of costs under all approved, quality cancer trials.

The Honorable Albert Gore, Jr.

January 29, 1998

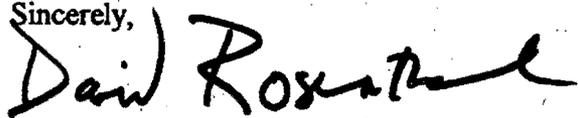
Page Two

Last year, we marked a twenty-five year turning point in the War on Cancer, with the announcement of the first sustained downturn in deaths from cancer - a direct result of steady, but uncoordinated efforts to apply the knowledge that basic research has brought us in three main areas: cancer prevention, early detection, and improved treatments. The American Cancer Society believes that we can accelerate this trend significantly by the year 2015 - perhaps cutting the rate of lives lost to cancer to half the current rate. To achieve those goals the ACS appointed a Blue Ribbon Advisory Group and asked them to examine community cancer control both inside the Society and throughout the nation. The Society intends to provide national leadership in formulating a plan that helps us reach those goals, and has fully committed our organization's resources to meeting these goals, in collaboration with our cancer fighting partners in the public and private sectors.

Finally, this announcement reinforces the important message that cancer is a national priority. More than 1500 people die each day from cancer - that is a national crisis which deserves our immediate response as a nation and must be funded accordingly. As you are aware, the American Cancer Society is fighting to enact bipartisan comprehensive national tobacco control legislation that will protect children and the public health. We must support our National Cancer Program, including the proposals you are announcing today, and top priority should be given to see that these initiatives move forward, independent of funding provided through any national tobacco control legislation.

Thank you for your leadership.

Sincerely,



David Rosenthal, MD  
President



# National Prostate Cancer Coalition

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

*Honorary Co-Chairman*  
Jon Huntsman

*Chairman*  
Robert J. Samuels

*Honorary Co-Chairman*  
Michael Milken

January 19, 1998

Letters to the Editor

## PROSTATE CANCER, A CASE OF DEADLY NEGLECT

In December 1997, President Clinton, with holiday reflections on the loss of his mother to breast cancer, outlined Medicare reforms that will make cancer screening less expensive for the 39 million Americans. Beginning in January 1998, under the 1997 Balanced Budget Act, Medicare will cover the costs for regular tests for breast, cervical, and colorectal cancer.

There has been a glaring omission in this act. In 1997, almost 42,000 American men died of prostate cancer. However, screening for this deadly disease will not go into effect until January 2000. The act inexplicably singles out and delays prostate cancer screening coverage under Medicare until January 2000. There is no scientific, medical or logical basis for this delay.

The National Prostate Cancer Coalition (NPCC) strongly supports H.R. 2639, legislation introduced by Representative John Murtha to provide that Medicare coverage for annual screening for prostate cancer begin in 1998.

The National Prostate Cancer Coalition supports this critical legislation to advance prostate cancer screening coverage to 1998 for three reasons.

**First, the key for surviving prostate cancer is early diagnosis and treatment.** While detection can be difficult and there needs to be more research money to improve diagnostic tests and treatments, annual screenings under Medicare are extremely important tools for men and their doctors for combating the disease. Congress has already recognized the importance of annual screenings by coverage starting in the year 2000. This first step of early diagnosis is critical, because health care delayed is health care denied.

**Second, there is no justification for delaying screening until the year 2000.** The Balanced Budget Act of 1997 provides for annual screening for breast cancer, diabetes, osteoporosis, pap smears and pelvic exams starting in January, but singled out prostate cancer for delay until 2000. In the meantime, an additional 12,000 men each year will be put at unnecessary risk from prostate cancer that may go undetected because of this two-year delay. Quite simply, moving annual screening under Medicare to 1998 can help save thousands of men. One of them may be you -- your son, your father, or your husband.

**Third, a simple fact regarding men's health is that too many men put off or avoid going to the doctor.** Too often this attitude hurts their health and takes their lives. By putting off annual prostate screening coverage, Congress is making the same health mistake too many individual men make - and risking the lives of thousands of constituents.

*Office of the Chairman:*

8509 Woodwick Court • Tampa, FL 33615 • Tel: (813) 886-2171 • Fax: (813) 886-2522 • bsamuels@gte.net

Page 2

Consider these statistics:

- Prostate cancer is the second leading cause of death of men in America
- Every 90 seconds a man will be diagnosed with prostate cancer in this country
- Every 14 ½ minutes a man will die of prostate cancer
- In 1997, more than 210,000 men were diagnosed with prostate cancer
- During 1997, 41,800 men died of prostate cancer
- Prostate cancer death rates are twice as high among African American males

More men than ever are now being diagnosed with prostate cancer in their 50's and 60's – in the prime of their lives. The physical, emotional and financial toll on these men, their families and society is incredibly high. In 1996 the estimated cost of prostate cancer was about \$3.7 billion .. \$2 billion was for hospital and physician care .. \$200 million for nursing home care and \$200 million for prescription medicines.. The remaining \$1.3 billion represent losses to families and to society in experience, productivity and wages.

Yet, prostate cancer receives the least funding per patient of all the major cancers, only 3.61% of all cancer research funding. *Put another way, prostate cancer accounts for 25 percent of all newly diagnosed cancer cases each year, but receives just 3.6 percent of the federal dollars for cancer research.*

Research funding for disease is never adequate but when compared to the funding dedicated to other major diseases like \$550 million for breast cancer, and \$1.6 billion for AIDS, \$80 million for prostate cancer is clearly underfunded.

We are working at the state level with our elected officials to develop support for prostate cancer. *Florida has the second highest incidence of prostate cancer in the country.* During 1997, 25,400 men in Florida were expected to be diagnosed with prostate cancer. That is twice the incidence rate of breast cancer. And yet, according to the 1998 Florida Cancer Control and Research Advisory Council's Florida Plan: *"At this time, there are no federal or state-funded programs relating specifically to prostate cancer."*

While we support the funding for research in breast cancer and AIDS – two diseases with similar number of annual deaths as prostate cancer. But if funding does not dramatically increase, tens of thousands of men each year could die while research that could lead to a cure or better treatments languishes. This is unacceptable.

We need your help today! I invite you to join with us to urge Congress to increase funding for prostate cancer research and to start Medicare prostate cancer screening in 1998.

Bob Samuels, Chairman  
National Prostate Cancer Coalition  
Tampa-813-886-2171 – Washington -888-245-9455

JOHN D. ROCKEFELLER IV  
WEST VIRGINIA

File VP Cancer  
Event

United States Senate  
WASHINGTON, DC 20510-4802

# FAX COVER SHEET

Tamera S. Luzzatto, Legislative Director  
Office of Senator John D. Rockefeller IV  
531 Hart, US Senate  
Washington, DC 20510-4802  
Phone: 202-224-9833 or 202-224-6472  
Fax: 202-228-4656

TO: Chris Jennings  
OFFICE: Nancy Ann DeParle  
Date: Judy Feder  
Number of Pages (including cover sheet): 6

1/29/98

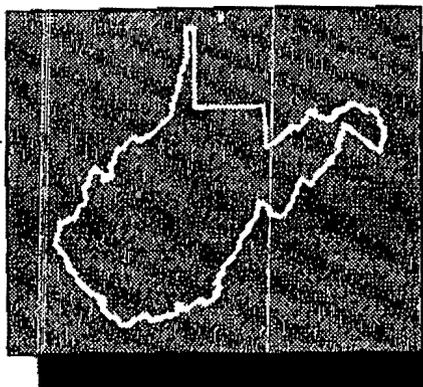
MESSAGE:

P.S. See also 5:30 or  
so for Mary Elk party in  
Finance Comm. Room

Might I'd share show-and-tell  
from Rockefeller Center's health department.

First, thank you so much to Chris  
and Nancy Ann on the cancer trials decision.

And being Mary Elk's last day (👀),  
what a nice tribute -- along with the  
Pres's major focus on health care continuing.  
Best, Tamera



**JAY ROCKEFELLER,  
U.S. SENATOR FOR WEST VIRGINIA**

# NEWS

WASHINGTON OFFICE, PHONE (202) 224-6472 • CHARLESTON OFFICE (304) 347-5372

**IMMEDIATE RELEASE**

January 29, 1998

Contact: Kassy Kelley  
(202) 224-6101

## **ROCKEFELLER, GORE ANNOUNCE HISTORIC PUSH IN WAR AGAINST CANCER**

WASHINGTON — At the White House today, U.S. Senator Jay Rockefeller joined Vice President Al Gore to announce a historic, two-pronged initiative to step up the nation's battle against cancer. Gore announced that President Clinton would propose a \$4.7 billion increase in funding for cancer research at the National Institutes of Health (NIH) and would support Rockefeller's initiative to expand Medicare to cover clinical cancer trials for its recipients.

"Today's proposal will have a profound impact on the lives of thousands and thousands of cancer patients and their families," Rockefeller said. "My view has always been that every cancer patient should have access to the best treatment available. Unfortunately, as we all know, that's not always the case. But the proposal announced today will help elderly cancer patients get access to some of the most effective clinical trials in the world. That's important progress."

More than 40 percent of Americans will be diagnosed with cancer during their lifetimes, and more than 20 percent will die from it. Medicare beneficiaries account for more than 50 percent of cancer cases, and for 60 percent of the half-million Americans who die of cancer each year. Scientists have made important strides toward fighting many cancers, but a long road still lies ahead. Today's announced \$4.7 billion increase for cancer research at NIH — a 65% increase over the next five years — boosts the potential of improving early detection methods, speeding the discovery of new cancer drugs and treatments, dramatically increasing adult participation in clinical trials, and providing all cancer patients and their care givers with easy access to the latest information on treating their diseases.

Last year, Rockefeller and Senator Connie Mack (R-Fla.) teamed up to introduce the "Medicare Cancer Clinical Trials Coverage Act of 1997," upon which the Clinton Administration is basing its own clinical trials proposal. That legislation would plan would direct Medicare to cover the patient costs associated with NIH-sponsored cancer clinical trials, ensuring beneficiaries have access to cutting-edge treatments.

"We've won a great many battles, but we can't stop until we win the war," Gore said. "That is why, even as we are balancing the budget and making tough cuts across the board, we must invest more in the war against cancer. We must give America's families new hope for a healthy future."

"Fighting cancer is tough enough. Treatment should be determined by what gives the patient the best shot at beating the disease, not what Medicare may or may not cover," Rockefeller said. "This proposal will allow our scientists to conduct groundbreaking research, and it will help elderly cancer patients benefit from the high-quality medical treatments that result from that research."

###

**FOR IMMEDIATE RELEASE**

January 29, 1998

**CONTACT:** Jim Whitney

(202) 224-6101

**Statement by U.S. Senator Jay Rockefeller (D-WV)  
White House Announcement of the Clinton Administration's  
Proposal to Improve Access to Cancer Clinical Trials  
for Medicare Beneficiaries**

What a way to start the day. More cancer research and better access to cancer clinical trials for the elderly.

I'm very pleased that the Administration, behind Vice President Gore's and Secretary Shalala's leadership, is fighting for major increases in cancer research funding and improved access to cancer clinical trials for Medicare beneficiaries.

I have the same optimism about the Administration's push for strengthened efforts to battle cancer this year as I did about its effort to expand kids' health care coverage last year.

As the Vice President laid out, there is real money in the Administration's budget for cancer clinical trials. I'm going to fight hard for this and I know my colleague Connie Mack, who has been such a leader on a whole range of cancer issues, will be right there with me.

This proposal will have a profound impact on the lives of thousands and thousands of cancer patients and their families.

My view has always been that every cancer patient should have access to the best treatment available. Unfortunately, as we all know, that's not always the case. But the proposal announced today will help elderly cancer patients get access to some of the most effective clinical trials in the world. That's important progress.

As we have heard this morning, the Administration's budget will provide Medicare coverage to cancer patients participating in a National Institutes of Health-sponsored cancer clinical trial. After a year, the National Cancer Policy Board would make recommendations to the Secretary of Health and Human Services, expanding the list of eligible trials.

Battling cancer is difficult enough. Treatment should be determined by what gives the patient the best shot at beating the disease, not by what may or may not be covered by Medicare. And today's announcement is an important step toward reaching that goal.

One of every four deaths in the United States is caused by cancer. Of the estimated half-million Americans who die from cancer each year, 60% are covered by Medicare. We cannot underestimate the need for a major, major effort in this area.

Basically, we're saying today that if you enroll in a NIH-sponsored clinical trial because it offers you the best treatment option, you will receive Medicare coverage to cover the same costs, such as hospital and physician fees, that would be covered outside of a trial setting. That's very exciting.

As many of you may know, legislation I introduced with Senator Mack last year goes further than what the Administration is proposing, but I am truly excited that this issue has been put on the list of Presidential priorities. And I want to again applaud the Vice President for working so hard to bring this about. Thank you.

###

Floor Remarks  
Senator Jay Rockefeller  
January 28, 1998

Last night, President Clinton gave us in his State of the Union speech a road map that I'm convinced is exactly where the American people want Congress to head as we start this new session.

Thanks to his leadership, we have good news to celebrate and the foundation to make even more progress for Americans and the country. We are finally done fighting about whether or when to balance the budget — instead, before our eyes, the federal deficit is rapidly disappearing and turning into the first balanced budget for thirty years. Our economy is in the best shape it's been in for years — inflation, interest rates, and unemployment all are down.

And none of this — a balanced budget, lower crime rates, a stronger economy — have happened by magic or by accident. Since 1993 when the President rallied Democrats on our own to pass a bold plan to slash the deficit, until last year when he brought together Democrats and Republicans to finish the job, tough decisions and hard work have been the only way to get these results.

Now, we must go forward and take on the next challenges. The President laid out in his speech the priorities and the dreams of Americans that spell out much of the work to be done.

Americans of all generations now look at the next century on the horizon, and want to be ready. Parents want their children to get the best education possible. Workers nearing retirement want the security of a good pension and decent health care coverage. And those who fall into the Baby Boomer and younger generations wonder whether there will be anything left over in Social Security and Medicare for them.

As President Clinton said last night, we now have the opportunity to act on these and other needs, and we should get to work right away.

Like the President, I want this Congress to press on with the idea that all Americans need and deserve access to affordable, quality health care. We made a tremendous leap last year by passing a program of \$48 billion to get up to 5 million children insured over the next ten years. In West Virginia, our Governor is leading the way to grab this opportunity and work with our legislature to put a plan into place so that our uninsured children will get good coverage and good medical care. Insuring our children is as fundamental to a future of economic growth and prosperity as decent roads or investing in technology.

The President laid out the next steps for health care. It's our time to pass legislation that ensures the most basic rights for Americans when they're in managed care. We're going to hear

insurance companies and their lobbyists run the same old ads with scare stories about "mandates" and "big government." But listen to the American people this time, and take your direction from them. They know that expecting access to specialists, to an ambulance, and to confidentiality about your medical records are far from over-reaching. This is called basic decency.

It's time to recognize the special problems and needs of people over 55, but who aren't old enough to get Medicare. Close to 15% of these older Americans are uninsured — at an age when you're more likely to have health problems and when insurers turn you away flat or charge the impossible.

The President has given us a proposal on what we can do for these very people — many who have watched their employers drop their retiree health benefits and downsize them out of a job. We should act on this for the people who need us to address these problems.

And we have a Commission on Medicare's long-term future with a charge to look even further ahead, so that the next generation and the generations after that can count on quality health care and a secure retirement.

I will serve on that Commission, with members from both houses on both sides of the aisle. And when I heard President Clinton urge Congress to resist spending any surplus until we fix Social Security, I applaud the idea and I add Medicare to our challenge. Through the work we did in the balanced budget bill, we have extended Medicare's solvency for another ten years. But the Commission must come to grips with the realities facing Medicare after that, and figure out how to sustain one of this country's greatest achievements of all — health security for all of our older citizens.

I hope that all of my colleagues in the Senate will look at the year with the focus, the energy, and the sense of direction that we heard in the President's speech last night. We know the ingredients that went into balancing the budget, reforming welfare, and making the commitment to insure our nation's children. We now must go forward, so our children get the best education possible; so parents get help like child care to juggle work with family responsibilities; so decent health care isn't subject to the whims of claims processors or the harsh effects of losing a job after age 55; and so we do the work now to shore up and strengthen Medicare and Social Security, to continue their role in making all of our generations feel secure.

# FAMILY UROLOGY™

A Publication of the American Foundation for Urologic Disease

**SPRING 1996**



## **COMBINED HORMONAL THERAPY**

*Colonel David G. McLeod, M.D.*

## **TEAM UP AGAINST PROSTATE CANCER**

## **PELVIC MUSCLE EXERCISES EXPLAINED**

*Kathe Wallace, P.T. and Jane Frahm, P.T.*

---

## **Clinton Presidential Records Digital Records Marker**

---

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

---

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

---

# FAMILY FOCUS

®

A publication of the American Foundation for Urologic Disease

**WINTER 1997**

## **Collagen Injection Treatment for Incontinence**

By Jacek L. Mostwin, M.D.

## **Impotence: A Problem You Can Deal With**

## **Unitas Leading the Charge, Educating Men on Prostate Health**



---

## **Clinton Presidential Records Digital Records Marker**

---

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

---

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

---

# File Prostate Cancer

## PROSTATE CANCER

### I. THE NUMBERS

Prostate cancer is the most commonly diagnosed cancer among American men and the second leading cause of cancer death.

- \* Projected 1997 Incidence- 210,000
- \* Projected 1997 deaths- 42,000
- \* Incidence Trends-
  - o 176% increase from 1973-93
  - o Sharp increase from 1989-93
  - o Downturn in incidence since 1993
- \* Mortality Trends-
  - o 23% increase from 1973-92
- \* Death Rates by Age Groups
- \* Survival-
  - o related to stage at diagnosis
  - o local stage- 10 year survival, 75%
  - o distant stage- 10 year survival, 15%

1/5 men.

72 years.

### II. RISK FACTORS

- \* Age X
- \* Family History
- \* Others, diet?????

### III. EARLY DETECTION TOOLS

- \* Digital Rectal Exam (DRE)
- \* Serum Tumor Markers
  - o PSA (Prostate Specific Antigen)
- \* Evaluation of the effectiveness of screening- Lack of scientific evidence that screening saves lives

### IV. SCREENING RECOMMENDATIONS

- \* Lack of a recommendation- U.S. Preventive Services Task Force, Canadian Preventive Services Task Force, American College of Preventive Medicine, and American College of Physicians
- \* Positive recommendation for screening- American Cancer Society and American Urological Association

V. TREATMENT OPTIONS

- \* Watchful Waiting
- \* Radiation therapy
- \* Radical prostatectomy
  
- \* Side effects of treatment
  
- \* Evaluation of the effectiveness of treatment options-  
lack of evidence

VI. THE SEARCH FOR ANSWERS

- \* PLCO Trial- NCI: Does screening reduce mortality?
- \* PIVOT- VA, compares the effectiveness of watchful  
waiting and radical prostatectomy

revised

You might want to call Dan Waldo re. New Reg

Ideas

**Announce Long-Term Care Initiative.** An important, but relatively unaddressed, effect of the aging of the Baby Boom generation is the incredible strain it will place on long-term care systems. The President could announce an initiative to: (a) encourage private savings and insurance -- offer long-term care insurance through Federal Employees' Health Benefits Plan; and (b) provide assistance to families that care for their elderly parents by providing respite care tax credit (still in development). This announcement could coincide with the release of a DHHS study documenting the impact and strain of caregiving on families. Note: because the tax credit has budget implications, it has to go through an NEC/DPC process before going forward.

Cost issues, need offsets

**Approve the 25th State Children's Health Insurance Program.** As of June 19, 20 states have had their plans approved; within the next two to three weeks, we will have hit the 25th -- half of the states, maybe 2.5 million children estimated to be covered by the states (still checking). We could release another progress report, maybe bring in the Governors, or bring in families who have already been helped by the program.

**Linking Race and Health Initiative with Children's Health Outreach.** Nearly half of the children eligible but not enrolled in Medicaid are minorities. In conjunction with a release of an HHS report that includes successful models for outreach for uninsured minority children, we could announce (a) clarifications of Medicaid eligibility (i.e., possibly the public charge issue and the lack of a requirement of parents SS numbers) that will make families with immigrants less worried about enrolling their children; (b) Hispanic language outreach messages and materials; and (c) a public-private partnership to enroll hard-to-reach children (e.g., get commitments U.S. Soccer League, minority religious organizations; etc.)

**Announce Allowing All States to Cover Two-Parent Families in Medicaid.** We will hopefully be able to bridge an impasse about publishing the "100-hour rule" reg. This will allow the 17 states who did not have an 1115 welfare waiver before welfare reform to have the option of expanding coverage to two-parent families under Medicaid.

Regs coming out.

- Families w/ state-by-state
- " = CMS (SCMB)
- Challenge Commission to do something -- Medicare
- HIPAA enforcement - PETERP
- Rural
- Disability - New conference with incubator purchase

File: ~~8~~ Prostate  
Cancer

# National Prostate Cancer Coalition

*Working Together to End Prostate Cancer as a Serious Health Concern for Men and Their Families*  
1156 15<sup>th</sup> Street, N.W., Washington, DC 20005

**Date:** January 13, 1998

**To:** Chris Jennings

**Fax:** (202) 456-7431

**From:** Jay Hedlund

**Phone:** (202) 463-9455

**Fax:** (202) 463-9456

**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**



# National Prostate Cancer Coalition

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

## 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).

- ◆ **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**

1156 15th Street, NW • Suite 905 • Washington, DC 20005 • 202-463-9455 • Fax 202-463-9456 • [www.4npcc.org](http://www.4npcc.org)

# National Prostate Cancer Coalition

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

## Testimonials of Prostate Cancer Survivors & Spouses

- **H. Norman Schwarzkopf, U.S. Army general, retired**  
*"The PSA test is important, but by itself it is not 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."*

- Tobacco - np
- Surgeon General
- FDA Commissioner - np → implementation
- Organ allocation - np
- NIH - budget - sb
- diseases - cancer, - sb
- AIDS - ?
- Regulation - np
- HIPPA enforcement - np
- Children's Hospitals - np
- Quality / Genetics. - sb
- ADAPT. - np
- Medicare Comm JL
- Medicare JL
- Voluntary Purchasing Coops. NP
- Long-Term Care JL
- Children's Health Implementation JL
- BBA Implementation. NP
- Mental Health SB
- Race Health
- Cancer Clinical Trials SB

FDA Comm.  
Organ reall.

QRA  
FDA Ref

Surgeon General  
~~Tobacco~~

Statement of  
**Col. David G. McLeod, M.D.**

Chief, Urology Service  
Walter Reed Army Medical Center  
Washington, D.C.

For a hearing on  
**Prostate Cancer Prevention and Treatment**

Before the  
**Special Committee on Aging  
United States Senate**

September 23, 1997

The opinions and assertions contained herein are the private views of the author and are not to be construed as reflecting the views of the U.S. Army or the Department of Defense.

Mr. Chairman and Members of the Committee:

My name is Colonel David G. McLeod, M.D. I am Chief of Urology at Walter Reed Army Medical Center and Director of the Center for Prostate Disease Research at the Uniformed Service University of the Health Sciences.

The Center for Prostate Disease Research (CPDR) was established in 1991 to manage cooperative research efforts of the Tri-Service Medical Centers. The CPDR is currently funded through the U.S. Army Medical Research and Materiel Command and the Henry M. Jackson Foundation for the Advancement of Military Medicine. Over the years, Congress has provided a total of \$23 million for CPDR activities. The Center is currently involved in a variety of activities including the implementation of a multi-center data base to analyze treatment outcomes on prostate cancer patients, the establishment of a clinical research center, and establishment of collaborative epidemiological and basic research on prostate cancer. The Center is rapidly becoming a vital resource for the improved understanding of prostate disease.

I am here today to discuss the treatment of prostate cancer and the role that innovations in treatment are playing in improving patient outcomes.

As Doctor Crawford mentioned in his testimony -- prostate cancer is very common among older men. One-in-five men will develop prostate cancer in their lifetime. Most prostate cancer patients will be over 65 when they are diagnosed and will survive 10 or more years with the disease. However, a significant percentage will be diagnosed when they are still relatively young. For most prostate cancer patients, their survival will depend on whether they get early detection or treatment. Many patients will be diagnosed late or to have a rapidly-progressing form of the disease.

The good news about prostate cancer is that when detected early in a low stage and grade, it can be effectively "cured" in 80 to 90 percent of patients through surgery or radiation. This is a remarkable result when you think of how rare it is with cancer that we are able to talk about "cures".

There is even more good news: with the advent of the PSA test, a larger proportion of patients is coming to us at earlier stages of the illness. This detection has helped us provide earlier treatment with a greater rate of success. This year, the Congress extended Medicare coverage to early detection of prostate cancer, effective in the year 2000. You and your colleagues are to be commended on this significant step, because it will

make prostate cancer tests completely available to that large portion of men with the disease who are of Medicare age. I only wish that we could advance the date when Medicare will begin paying for these tests.

There is a portion of patients whose treatment will be effective in eliminating the prostate cancer; however, they will have side-effects from treatment that may affect their quality of life -- mostly urinary incontinence or impotence. For these reasons, not all patients diagnosed with prostate cancer will choose definitive treatment. For older patients, with less than 10 years of life expectancy or those with serious health problems, it may be more appropriate to monitor the progress of the disease and withhold surgery or radiation if the disease does not appear to progress rapidly. It is particularly important that patients be given information about their treatment options and participate actively in the decision-making.

While there are complications for some patients, treatment outcomes for prostate cancer are improving dramatically. The advances we are making in forms of treatment are improving the effectiveness of treatment while reducing complications for patients. Earlier detection of the disease and better patient outcomes from early treatment are lessening many of the concerns that were raised in the past about prostate cancer detection and treatment.

520-780

I would like to start my discussion of treatment advances by describing how we stage and grade prostate cancer and how this information is used to guide the choice of treatment. Doctor Crawford talked about detection -- using the PSA blood test and the digital rectal exam (DRE). A positive result from the PSA and/or DRE is generally followed by a biopsy where we take samples of tissue from the prostate for the pathologist to examine. There are two important questions we need answered in this process:

- Stage -- Is the cancer still confined to the prostate gland or has it extended beyond the gland and into adjoining tissue, pelvic lymph nodes, or bone?
- Grade -- Is the form of the cancer cell -- the degree of cell differentiation -- one that would suggest very rapid progression or one that will progress slowly?

Well-differentiated cancers which are still confined to the prostate gland have the greatest chance of successful treatment. A recent study published in the *Journal of the American Medical Association*, for example, showed that 75 to 97 percent of the patients with organ-confined, well-

differentiated cancer were still alive 10 years after radical prostatectomy<sup>1</sup>.

Cancers that have spread beyond the prostate are much less likely to be eradicated. Cancer that has metastasized to the bone will nearly always be fatal.

Once we know the stage and grade of the cancer, as much as can be determined from our clinical evaluation, we discuss treatment options with the patient and his family. There are four basic treatment choices: surgery, radiation, "watchful waiting," and hormonal therapy.

- **Surgery** -- surgical removal of the entire prostate gland (radical/total prostatectomy) -- is a treatment that is appropriate if the cancer is still clinically confined to the prostate. Survival is quite good, and only a minority of men have complications.
- **Radiation** -- an alternative to surgery, that may also be effective with some cancers that have spread beyond the prostate gland to surrounding tissue. Outcomes and complications are generally similar to those for surgery.
- **Watchful waiting** -- a form of treatment in which the physician actively monitors the disease - through regular patient visits and

---

<sup>1</sup> Krongrad A, Lai H, Lai S. "Survival after radical prostatectomy," *Journal of the American Medical Association*. 1997;278:44-46.

testing. With this approach, surgery or radiation will be withheld unless the disease begins to progress.

- **Hormonal therapy** -- blocks male hormones that "feed the cancer" thus slowing the growth of the cancer. The optimal treatment for advanced prostate cancer involves combination hormonal therapy (including oral anti-androgens) to completely block production of male hormones. Treatment of advanced prostate disease cannot cure the cancer, but it has been shown to extend life expectancy and improve quality of life for men with late stage cancer. One study I was involved with showed that the addition of oral anti-androgens in combination with an injectable hormonal compound (an LHRH agonist) to block production of testosterone from the testicles improved survival of patients with advanced prostate cancer by 26 percent. Other studies have shown mixed results in the use of anti-androgens in combination with orchiectomy (surgical castration).

In a perfect world, we would limit surgery to cases in which we were sure the cancer was entirely confined to the prostate. Unfortunately, we cannot always be sure of the stage prior to surgery. Occasionally we

discover cancer in surrounding tissue or pelvic lymph nodes when we examine the prostate and nodes after surgery. Significant improvements in diagnosis and staging prior to surgery are helping to reduce the number of prostate cancers that are found to extend outside the prostate. For example, laproscopic surgery can now be used in selected patients to remove the pelvic lymph nodes prior to prostatectomy or radiation to determine whether they contain cancer cells. Surgery can be avoided in patients with evidence of cancer in the lymph nodes.

In recent years, we have made a number of significant strides in advances treating prostate cancer. I would like to briefly describe these for you and then discuss their importance in improving the chances that treatment will be effective in curing the cancer with minimal side effects.

- **"Nerve-sparing" prostatectomy** -- a surgical technique that was pioneered several years ago by Dr. Patrick Walsh at Johns Hopkins to reduce the chances of impotence or incontinence in patients having surgery. In the past, surgeons generally cut through the nerve bundles around the prostate gland to remove the gland. In the nerve-sparing approach, the surgeon attempts to keep the nerves intact that are critical to potency. Studies of this technique have indicated that it reduces impotence and incontinence rates

among men having surgery. Unfortunately, there are still relatively few surgeons with extensive training in this technique.

- **Cryosurgery** -- an old technique that has recently become popular again, involving the freezing of the prostate gland to kill cancer cells. Since a fellow panelist is discussing cryosurgery, I will not elaborate on it here.
- **External Beam Radiotherapy** -- Better methods are being developed to localize the prostate for radiation treatment (conformal radiotherapy). Also, techniques utilizing different types of radiation energy are being investigated -- neutron and proton therapy.
- **Brachytherapy** -- a form of radiation therapy where radioactive seeds are implanted in the prostate gland to kill cancer cells. Patients have the seeds implanted during one sitting, rather than coming in repeatedly for external beam radiation. The latest technique in brachytherapy is one whereby seeds are placed in the prostate with ultrasound guidance.
- **Neoadjuvant hormonal therapy** -- Recently, the FDA has approved the use of combination hormonal therapy with radiation in the treatment of early stage cancer. The hormonal therapy slows

the growth of the cancer and shrinks the prostate to enable more effective therapy by radiation. Studies are on-going using neoadjuvant therapy prior to radical prostatectomy.

- **Chemotherapy** -- Chemotherapeutic agents have usually been used with patients who have metastatic prostate disease and are no longer responding to hormonal therapy. Recently a chemotherapy drug was approved by the FDA for use in managing pain and reducing PSA levels for patients with advanced prostate disease.
- **Immunotherapy and Gene Therapy** -- There is a potential for the use of immunotherapy and gene therapy in preventing prostate cancer. Additional research money is needed to realize this potential.

These treatment advances are encouraging, and offer great hope that we can be quite successful in curing prostate cancer for many patients at some point in the not too distant future. Unfortunately, there are a number of government imposed barriers that may stand in our way. Let me discuss a few of these barriers that I am most concerned about.

- Delayed Medicare coverage of early detection with the PSA test:

Unfortunately, when the Congress extended coverage to the PSA test earlier this year, they stopped short of putting it into effect immediately along the other preventive benefits. The 3-year wait before the new coverage goes into effect seem unnecessary. A patient who appears at the doctor's office after they have begun to experience pain or difficulty in urination may have prostate cancer that is too advanced for a cure. Early detection has been very helpful in getting patients in early enough to treat them effectively. I would think Medicare costs would be lower if these patients were detected early and treated early than if they were to progress to advanced cancer and have significant, and expensive, complications associated with end-stage disease. Congress should accelerate the timetable to put this benefit into effect in 1998.

- Inadequate Medicare coverage of treatment -- Medicare does not cover some forms of prostate cancer treatment. Of particular concern is the failure of Medicare to cover oral anti-androgens that are now showing promise in neo-adjuvant therapy with radiation and possible with surgery. Back in 1993, when the Congress enacted coverage for oral cancer drugs, it neglected to cover oral

anti-androgens. This omission is because the definition was limited to drugs that *substituted* for injectable drugs, and it did not include drugs (like oral anti-androgens) that *supplement* injectable drugs. As a result, there is a considerable bias in Medicare payment in favor of less-effective forms of treatment. Medicare should not be in the business of picking some forms of treatment over others. It should cover all approved and effective treatments for prostate cancer and let the medical community decide what is appropriate care for particular patients.

- Underfunding for prostate cancer research -- Until last year, prostate cancer research received only one-fourth as much funding as breast cancer research. Then in fiscal year 1997, Congress appropriated \$38 million for prostate cancer research through the Department of Defense. Unfortunately, the appropriation for fiscal year 1998 is still uncertain at this time. When signs are pointing to the chance for significant breakthroughs in prostate cancer detection and treatment, we should not be starving the research community dedicated to this problem. We have made great progress, but we need to make much more progress to begin to control this cancer that ravages so many older men.

I commend the Chairman and Senator Shelby, and appreciate the interest other members of the Committee have shown in having this hearing today. I will be pleased to support any activities this Committee can undertake to help us solve the remaining problems in tackling prostate cancer.