

National Prostate Cancer Conference

Influencing Government and the NHS

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Who Are We?

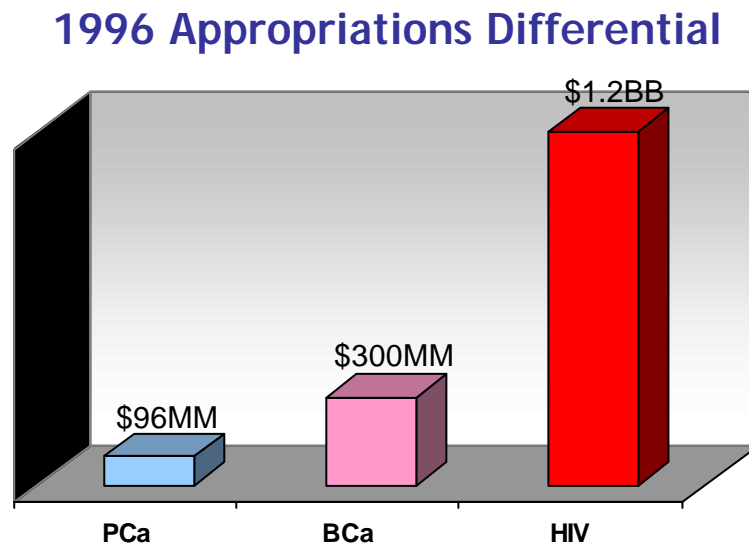
- NPCC is the largest U.S. nonprofit dedicated to prostate cancer awareness, outreach and advocacy.
 - ? We were formed in 1996 and moved to our nation's capital in 1997.
 - ? When we were formed no other organization was invested in prostate cancer public policy, especially acquiring federal research appropriations.
 - ? Now we say, "We're Taking Care of the Biggest Thing in Men's Health."

- NPCC is supported by generous individuals, corporations and family foundations.
 - ? We are transitioning toward greater participation from non-pharmaceutical corporations, in cause marketing partnerships.
 - ? We currently receive no government subsidy.

What Did We Want to Do?

Change Public Policy

- Research appropriations & oversight
 - Absolute dollars



What Did We Want to Do?

Change Public Policy cont.

- Research appropriations & oversight
 - Accountability
 - Economies of scale
 - Increase efficiencies
 - Decrease duplications of effort
 - Increase collaborations – 2 federal agencies (the Department of Veterans Affairs the National Institutes of Health, with 27 Institutes/Centers most) claiming prostate cancer research.
 - Private sector, including industry, invests dollars that match.
 - In 1997, add the Department of Defense as a significant player.

What Did We Want to Do?

Change Public Policy cont.

- Patient care
 - Access
 - Medicare reform
 - Oral anticancer medications
 - A drug benefit that makes sense for seniors
 - Federal/State mandated insurance coverage for early detection
 - Social Security law says “either PSA or DRE annually”
 - More than 20 states lack coverage mandates
 - Availability
 - Since men are couch potatoes, bring care to the couch
 - Early detection – “The Drive Against Prostate Cancer”

What Did We Want to Do?

Change Public Opinion

- Impact different constituencies
 - Patients/Survivors
 - Family members, particularly women
 - “Behind every man seeking health care is a woman with a two by four (wood girder).”
 - Affiliated
 - African Americans
 - 65% higher incidence and twice the death rate of White males
 - Family History
 - Risk with three family members approaches unity in some studies
 - Veterans (Asian Theater)
 - Is it an independent risk factor or an aggregating risk factor
- “Underscreened”
 - 60+% have been screened once
 - 25% are current over 5 years

How Did We Do It?

Direct Lobbying

- Members
 - NPCC personal relationships
 - Political Action Committee (the “notorious” PACs)
 - Grass Tops (CEO to Member)
 - Grass Roots
 - Staff (to Staff)
 - Partner relationships – our advocacy messages are included in others’ platforms, like among veterans’ organizations
 - “Spring Training”
 - Collaborations with other organizations when common interests are threatened
 - Department of Defense cancer research programs reduction threatened in FY 2005 – sadly led by a Senator with prostate cancer.
 - We didn’t join ‘em; we beat ‘em

How Did We Do It?

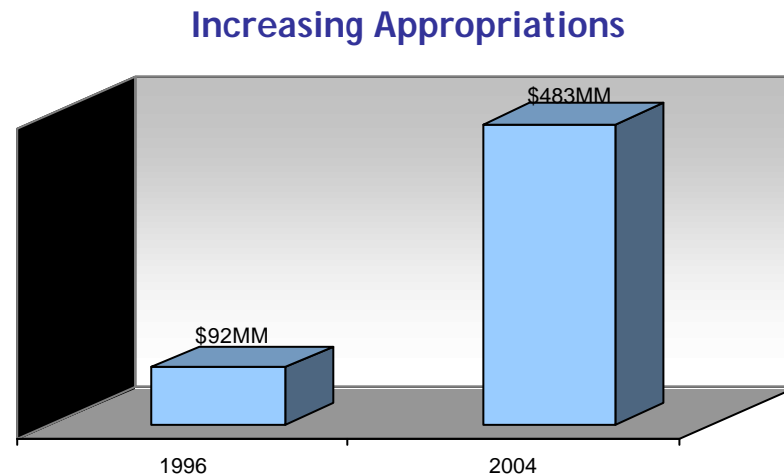
- Awareness/Education Strategies to bring constituencies to the table
 - Website
 - Conferences/Meetings
 - Email recruitment for lobbying
 - Targets users in key Congressional districts and states
 - Media outreach
 - 25 MM media impressions in 2001; 2 BB targeted for 2004
 - Partner relations
 - Cause marketing
 - Significant inbound growth since 2003; 2004 marks beginning of major outbound push

How Did We Do It?

- Outreach Strategies
 - “Drive Against Prostate Cancer” – a national mobile medical office offers early detection to 10,000 men annually, 7.5% have PSAs above acceptable cutpoints.
 - Goal = Growth from one vehicle to four by end 2005, 40,000 participants
 - Goal = Greater penetration in communities
 - Goal = Greater use in research
 - Goal = Expanded platform for men’s health without diminishing brand identity
 - “*aware*” – has >40,000 subscribers, 2000% growth in two years.
 - Goal = 150,000 by end 2005
 - Goal = greater participation in research, 60% are prostate cancer patients

What Did Our Advocacy Efforts Accomplish?

- Greater dollars
 - Five-fold increased appropriations, to about \$500 MM in 2004



What Did Our Advocacy Efforts Accomplish?

- Greater oversight/accountability
 - Professional judgment budgets for funding agencies, mandated by Congress
- Prostate Cancer Research Funders Conference, a voluntary collaboration in which the capacity of the whole is greater than the capacity of any one part.
 - All federal players/agencies are at the table, represented by their chief (research) executives
 - Some private sector representation
 - The model emphasizes potentials and problems when all the smart – and ego-driven – people are at the table
- Some federal changes in drug coverage and drug benefits, but not for seniors most in need

Problems

- Grass Roots – Few buds; fewer flowers; lots of weeds
- Perennial (or evergreen) support, especially cause related marketing