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# VIRGINIA PROSTATE CANCER COALITION

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Volume 2, Issue 1

*Making Prostate Cancer History in Virginia*

March 2008

## Chairman's Corner

### ANNUAL REPORT 2007-2008

#### Virginia Prostate Cancer Coalition

*Dick Gillespie*

As VPCC goes into its sixth year, a review of Coalition accomplishments shows much has been accomplished. Yet Virginia still has the 8th highest PCa mortality rate in the U.S. An estimated 4,430 Virginians will be diagnosed; 630 Virginia men will perish. Some of these men, especially minorities, will be uninsured or underinsured. Our stalwart volunteers continue to devote countless hours to spreading the word throughout Virginia about the necessity of early diagnosis and treatment. Once again, we will roll up our sleeves and get back to work promoting patient advocacy!

Here are some of the Coalition's priority programs over the past 12 months, and ones that we will be working on this year.

At the federal level, the Coalition has emphasized adequate funding for the National Institutes of Health (NIH), the National Cancer Institute (NCI), and the Center for Disease Control (CDC), and the Congressionally Directed medical Research Program (CDMRP) administered by the Department of Defense. <http://cdmrp.army.mil/pcrp>. While Administration cuts in spending for these organizations last year (FY 2007) were avoided, this does not seem to be the case this year.

*continued on page 2*

## Spotlight on Virginia

### 2006 Sites of High Prostate Cancer Mortality Rates in Virginia

*Carol Noggle*

Nationwide, the American Cancer Society data continues to show that Virginia still ranks 8<sup>th</sup> highest for prostate cancer death rates.

The VDH Division of Health Statistics has provided mortality rates for every Virginia County and independent city. There were 686 deaths from prostate cancer in 2006 – less than in 2005 but more than in 2004.

The 5 locations with the highest mortality rates were in Middlesex County, Bath County, Williamsburg City, Petersburg City, and the County of King and Queen.

The rates for these five were all at least three times higher than for Virginia as a whole. This data can help us determine targets for education and awareness. ❖

## VPCC Annual Meeting

Our 6th Annual Meeting was held on March 10 and included a review of our activities, a financial report, Brenda Hagg's report about the pro bono legal services provided by LINC, Nicole Palya's report from TAP of concerns about prostate cancer medication costs, and the election of Board members including a new member **Philip LaBonte**. The Annual Report is included in this newsletter. We very much appreciate being able to meet at the Glen Allen ACS office. ❖



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Alvin Chin, Jim Waldenfels, Leo Shanley, Ray Walsh and Dick Gillespie participated in the IMPaCT Conference (Innovative Minds in Prostate Cancer Today), a celebration of the impressive initial ten year record of the Prostate Cancer Research Program of the CDMRP. Each of these individuals has participated as prostate cancer survivors in two or more of the annual peer review panels that figured importantly in the selection of research projects for this disease.

Alvin Chin also participated in the 2007 Scientist-Survivor Program sponsored by the American Association for Cancer Research for a third year of VPCC participation. Both of the above-cited activities helped create visibility for the Coalition in these important forums.

Several VPCC Board members, speaking as individuals, participated in FDA advisory committee hearings on the drugs Provenge and Satraplatin. While helping underscore the need for progress, our members were also a voice for moderation during the turmoil in the months following the Provenge hearing. Our interaction with the FDA advisory committees demonstrates the special role we can play because of our proximity to the FDA and our familiarity with the way government works.

Turning to the future, passage of the Manton Bills, H. R. 2131, Senate 1275, our top federal legislation priority, would provide early detection and treatment for the uninsured and underinsured like the programs that already exist for breast and cervical cancer.

VPCC is working closely with the National Association of State Prostate Cancer Coalitions (NASPCC) to exchange information on our activities and to identify where states could work together in approaching Congress. Coalition Vice Chairman Kathy Meade is an active member of the NASPCC Board.

Organizing volunteers in the eleven Virginia congressional districts to work more effectively with our congressmen and their staffs is therefore a top priority. We need to be in a position to provide timely, relevant information on the medical issues these congressmen are working on, and we need to be kept better informed on their priorities and positions. Particular emphasis will be on the three congressmen who serve on the House Appropriations Committee, Jim Moran (8<sup>th</sup> District), Frank Wolfe (10<sup>th</sup> District), and Virgil Goode (5<sup>th</sup> District). Our volunteers will also help us identify health fairs where we may participate. Board members have now identified these volunteers, and will be organizing and training them in the next several months. We are careful to remain within the accepted confines of patient advocacy.

At the state level, we worked in concert with a variety of partners on a number of initiatives to spread our message of early diagnosis and treatment of prostate cancer throughout

Virginia, especially to the state's underserved regions and minorities. Board members attended the American Cancer Society's legislative reception, and its State Lobby Day in Richmond in January. Other collaborators have included some state government entities, especially its Health Department (VDH) and its Comprehensive Cancer and Control Project, a source of some funds for outreach. Others include the Cancer Plan Action Coalition (CPAC), the Joint Commission on Health Care (JCHC), the Patient Advocate Foundation, UsTOO and Man to Man chapters, and local hospitals and cancer centers.

VPCC has been working with the CPAC: Carol Noggle on the Early Detection workgroup's programs, Kathy Meade with the Survivorship workgroup, and Barbara Dykes with the Treatment workgroup. We look forward to CPAC's November 2008 conference. Talks with key legislators on the JCHC are planned once the current legislative sessions are complete.

We are particularly pleased with our work in helping with the Virginia Department of Health programs to better serve underserved areas and individuals. From the \$50,000 budgeted in 2007 by the General Assembly programs for African-American community health forums were undertaken in Richmond, Norfolk and three programs in South Side counties. Some 150 attendees attended the Brunswick County site. Board member Henry Mack helped with the planning and organizing of the three Southside sessions.

Another event was a Community Education program on both breast and prostate cancer in late September, funded with a VDH grant of \$2,000. Collaborators included Fauquier Hospital, the new Lake Manassas Cancer Center and several other local medical organizations. Board member Carol Noggle worked with each of these collaborators in planning and conducting this symposium comprised of two physician panels as well as free breast exams for women and PSA tests for men. This event was highly successful, with over 50 men and women participating. We hope that our above-cited events will provide a model for future programs.

Coalition participation in two other events, the Marine Corps Marathon Health Expo last October and the African American Men's Health Forum in February of this year. For the Marine Corps Marathon VPCC and Dr. Charles Snuffy Myers' Foundation for Cancer Research and Education (FCRE) provided materials that were included in the goodie bags given to some 30,000 runners when they registered. More prostate cancer information was personally handed out to 4,500 competitors from our booth. Board member Jim Waldenfels, who took the lead in planning and implementing our operation, and other volunteers were able to engage a substantial number of men in serious discussion of this disease.

The Coalition was also active in the February 16<sup>th</sup> 2008 African American Men's Health Forum in Richmond. Attendance this year had jumped from 500 in 2007 to 900, a pleasant surprise to the event's planners and to the sponsor, the American Cancer Society. Board member Henry Mack once again was deeply involved in the planning of this event, and Coalition volunteers Basil Grant and Leo Shanley helped run our prostate cancer display. Some 190 copies of our Resource Guides were distributed. Prostate cancer was one of the diseases addressed in this session, and the many men who visited our display were serious in wanting to know more about the diagnosis and treatment of this disease. We came away feeling that we had really done some good in both of these events.

Coalition members and helpful friends presented information to employees of over twelve Virginia companies and government agencies, to health fairs, and to senior centers. We expect to increase that number in 2008. Board member Alvin Chin coordinates the expansion of education programs to businesses.

In our discussions with cancer survivors and with the Patient Advocacy Foundation (PAF), we see a serious need for funding for prostate cancer diagnosis and treatment of uninsured or underinsured Virginia men. This clearly is a need which should be addressed.

We plan to narrow the focus of the web site and newsletter. The former will focus more on our patient advocacy measures and programs: what federal, state and local governments are doing and how we are responding. For those readers who seek medical information, there will be links to other sites with these data. Our quarterly newsletters will be similarly focused.

After working for years on a shoestring budget and periodic grants from the state government or other nonprofit institutions that work on prostate cancer, we now are encouraging individual contributions. We will endeavor to plan our funding at times more convenient for supporters. Qualifying for the U.S. government's Combined Financial Campaign is under consideration. ❖

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**Virginia Prostate Cancer Coalition (VPCC)**

***www.vapcoalition.org***

**703-339-0508**

## ADVOCACY

**Call YOUR U.S. Representative. Ask him or her to co-sponsor HR 2131: "The Thomas J. Manton Bill"**

You can make this happen. It is easy.

Help get this bill out of committee and to the U.S. House Floor for a vote.

Who needs HR 2131?  
Uninsured or Underinsured Virginia Men

***For what?***

Prostate cancer tests  
Prostate cancer diagnosis such as a biopsy.  
Prostate cancer treatment

***What number do I call?***

202-225 – and your Rep's 4 digits\*\*

***What should I say?***

"I am concerned about men dying in Virginia. Virginia has the 8<sup>th</sup> highest mortality rate for prostate cancer in the U.S. In 2006, 686 men died of prostate cancer in Virginia. Virginia men who do not have insurance are likely to get diagnosed and treated too late for a cure. The Manton bill, HR 2131, will provide a program for these Virginia men.

Rep. Jim Moran and Rep. Tom Davis are co-Sponsors of HR 2131.

We need the remaining NINE representatives to help this spring 2008.

Watch progress here:

<http://www.govtrack.us/congress/bill.xpd?bill=h110-2131&tab=summary>

***Nine Remaining House of Representatives Members***

Rep. Rob Wittman 202-225-4261  
Rep. Thelma Drake 202-225-4215  
Rep. Bobby Scott 202-225-8351  
Rep. Randy Forbes 202-225-6365  
Rep. Virgil Goode 202-225-4711  
Rep. Bob Goodblatte 202-225-5431  
Rep. Eric Cantor 202-225-2815  
Rep. Rick Boucher 202-225-3861  
Rep. Frank Wolf 202-225-5136

KEEPING UP with Prostate Cancer in the News – Do you Yahoo? If you would like Virginia prostate cancer news, VPCC news, national news and advocacy issues and research you may wish to sign up for the vapcoalition yahoo group messages. Contact Kathy Meade to learn about subscribing -- [kmeade@vapcoalition.org](mailto:kmeade@vapcoalition.org) ❖

## VPCC Budget Report

	VPCC Budget Summary	Feb 29, 08
<b>ASSETS</b>		
Current Assets		
Checking/Savings		
Wachovia Bank		14,928.38
Total Checking/Savings		14,928.38
Total Current Assets		14,928.38
<b>TOTAL ASSETS</b>		<b>14,928.38</b>
<b>LIABILITIES &amp; EQUITY</b>		
Equity		
Opening Bal Equity		21,248.36
Retained Earnings		-5,674.82
Net Income		-645.16
Total Equity		14,928.38
<b>TOTAL LIABILITIES &amp; EQUITY</b>		<b>14,928.38</b>

	VPCC Income & Expenses	Mar '07 - Feb 08
<b>Ordinary Income/Expense</b>		
<b>Income</b>		
Contributions		
Contributions- Unrestricted		3,660.00
Total Contributions		3,660.00
Grants - Received		
Grants - Restricted		2,000.00
Grants - Unrestricted		300.00
Total Grants - Received		2,300.00
<b>Total Income</b>		<b>5,960.00</b>
<b>Expense</b>		
Corporate Fees/Taxes		130.00
Credit Card Fees - Chase		31.00
Dues and Subscriptions		25.00
Internet Services		455.30
Marketing		1,211.96
Meals and Entertainment		417.73
Meeting - exhibit booths		2,350.00
Postage and Delivery		414.21
Printing and Reproduction		420.00
Supplies		1,149.96
Total Expense		6,605.16
Net Ordinary Income		-645.16
<b>Net Income</b>		<b>-645.16</b>

## VPCC Calendar

March 29

Free prostate cancer screening; Mid-Rivers Cancer Center  
Montross VA 804-493-8880 for appointment.

April 19

American Cancer Society  
African American Men's Health Forum  
To register or for more information [www.cancerhealthforums.org](http://www.cancerhealthforums.org)

April 26

9:30 AM

VPCC sponsors Dr. Charles "Snuffy" Myers at Westminster UsTOO  
Contact: 703-497-0628 [chesterii@aol.com](mailto:chesterii@aol.com)

June 4

VPCC Board Meeting

More meeting dates and speakers are on the VPCC website.

<http://www.vapcoalition.org/Calendar.htm>