
VIRGINIA PROSTATE CANCER COALITION

Volume 4, Issue 1

Making Prostate Cancer History in Virginia

Winter 2009/2010

Chairman's Corner

Dick Gillespie

The last few months have witnessed highly successful Coalition activity in outreach and collaboration. In September, Coalition volunteers worked the Virginia State Fair in Doswell and, in November, our volunteers were active in the Marine Corps Marathon Expo in Washington, DC. Our ability to personally provide information on prostate cancer prevention and treatment to men is one of our most critical functions.

In 2009, several members were once again active in reviewing prostate cancer research proposals for funding under the Congressionally Directed Medical Research Program managed by the Department of Defense (DOD). In 2009, 161 proposals were approved for the \$80 million allocated to prostate cancer, as described in an article on page 3 of this issue. Please read the article for more information on this program and the need for additional funding.

Meanwhile, we are delighted to learn that work on the Virginia Comprehensive Cancer Control Project is underway. Staffers at the University of Virginia reportedly will launch the CDC work plan for this important initiative early in 2010. More on this project in future newsletters.

Provenge Availability

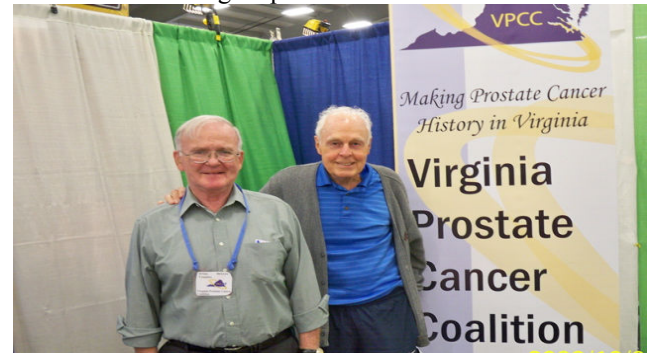
A Provenge clinical trial is now recruiting. The trial is: "Open Label Study of Sipuleucel-T," NCT00901342. "Inclusion Criteria" includes metastatic disease, castrate resistant, and life expectancy of at least 3 months. For "Exclusion Criteria" and other details, go to clinicaltrials.gov. Participating locations include Georgetown University and Sentara, Norfolk. The UsTOO December 2009 'Hotsheet,' available at ustoo.org provides an update on Provenge. For the right men, this could be a tremendous opportunity. Contact your doctor or the contacts listed on clinicaltrials.gov or dendreon.com/patient_resources/clinical_trials/



VPCC at work

Virginia State Fair:

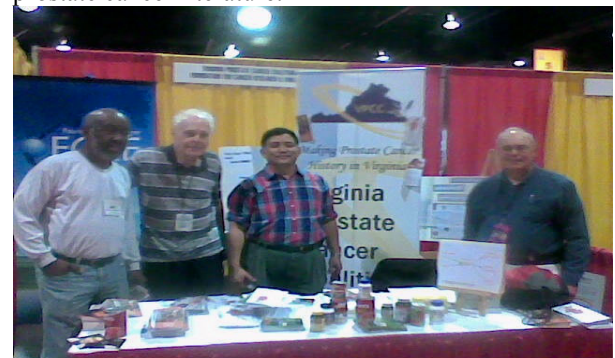
30 Coalition volunteers worked our display at various times during the 10-day Virginia State Fair. We were located on a desirable corner which made it easy for individuals to stop by and talk. Carol Noggle and our volunteers distributed literature to some 1,200 individuals from 67 counties and 23 cities. The Foundation for Cancer Research and Education and UsTOO once again provided resource materials.



Above, Leo Shanley and Dick Gillespie staff the VPCC booth at the Virginia State Fair.

Marine Corps Marathon Expo:

The Expo precedes the actual marathon and is visited by the marathoners, families, and friends. VPCC participated for the fourth time and once again was successful in reaching out to the public. This success derived from careful planning by our indefatigable Board member Jim Waldenfels and the spirited work of our volunteers. This year's Expo was held in the DC Convention Center and our booth was located at the entrance to the Expo area – a great location. Over 5,000 individuals came away with our prostate cancer literature.



Above, Bill Bright, Dick Gillespie, Alvin Chin and Jim Waldenfels in the VPCC booth at the Marine Corps Marathon Expo.

Active Surveillance - Helping Friends Understand

This is the second of a two part series. The first part is available in the Summer newsletter on www.vapcacoalition.org.

Jim Waldenfels

“Hi Mike, what’s up? What a coincidence. Just last night we were talking about you too and wondering how retirement is working out for you and Mary. I hope life is treating you well.” “Oh yes, retirement is fine, and we are seeing a lot more of our sons and daughter, but not everything is so great. In fact, that’s why I’m calling. Jim - I’ve got prostate cancer. I know you are dealing with that yourself, so I’m hoping you can help. Two of my golf buddies had surgery, and they’re telling me I need to get it out and get it into a jar. But my urologist is saying I’m a good candidate for something called ‘active surveillance.’ From the little I remember, it sounded like doing nothing to me. That’s not going to work, right? But I sure don’t want to risk those side effects if I don’t need to. Mary is worried, and frankly, I’m scared and confused as hell!”

How many of us have heard a story like that? Okay, maybe the urologist does not encourage active surveillance that often in the real-life version. Even though guidelines from their professional group, the American Urological Association, encourage discussion of that option with low-risk patients, based on impressive successes in accumulating research from major medical institutions, it’s a good bet that many urologists are continuing to press the fear button in mentioning the active surveillance option to their newly diagnosed prostate cancer patients; all the doc needs to say to spook most of us laymen is something like “We really can’t be sure whether the cancer might spread while we are deferring therapy.” That’s enough for many of us to say “Let’s forget about that!” But a growing number of urologists are heeding the guidelines and are aware of the research behind them, as well as outstanding outcomes among their own patients. We’re hearing more reports from patients whose doctors are encouraging the choice of an active surveillance approach and are fostering them along the way, especially in the vital first two or three years.

So how can we help our friends? PubMed, www.pubmed.gov, is a great free resource that covers all the published research on active surveillance, but most new patients are going to find it hard to use. The search is easy enough - just “prostate cancer AND active surveillance,” pulled up 527 hits, some as recent as last month; but understanding the medical terminology, learning which institutions are heavy-hitters in prostate cancer treatment and research, grasping the significance of the research, and just navigating through all the published papers can be daunting. That’s where a major but simple new resource comes in: a

tri-fold pamphlet from the Prostate Cancer Research Institute, entitled “What’s Your Type?” The pamphlet, which is available online at www.pcri.org, is a wonderful aid in quickly enabling new patients to see whether they fall in the low-risk group for which no immediate treatment is recommended (active surveillance), the intermediate risk group, or the high-risk group. But an especially worthy aspect of the pamphlet is the sound emphasis it puts on active surveillance, coupled with paragraphs highlighting the fact that treatments often have substantial side effects. All this is in the context of urging therapy for men with intermediate and high risk cases.

Editor’s note: See the article on page 3 of this issue on the new NCCN guidelines, placing added emphasis on active surveillance.

Strategic Planning

The VPCC Board of Directors will meet on January 26, 2010, for the purpose of updating the Coalition’s Strategic Plan. The meeting will take place at the Foundation for Cancer research and Education (FCRE) in Charlottesville, VA. If you have any suggestions for our strategic plan and/or wish to attend the meeting with the board, please e-mail Dick Gillespie at chesterii@aol.com.

VPCC Holds Board of Directors Meeting

On December 7, 2009, VPCC held a Board of Directors meeting. Bostwick Diagnostics, Glen Allen, VA, made one of its meeting rooms available to the Board. Present, and pictured below left to right, were Jim Waldenfels, Jim Kearns, Barbara Dykes, John Goulait, Kathy Meade, Dick Gillespie, and Alvin Chin. Also present was Carol Noggle. Business discussed included results of participation at the State Fair and Marine Corps Marathon, the need to update the VPCC strategic plan, and budgeting and fund raising. Scott Riccio from the Dendreon Corporation updated the Board on the status of Provenge (see the article on page 1 of this issue on the availability of Provenge through clinical trials). If you wish to attend future meetings of the Board, please e-mail Dick Gillespie at chesterii@aol.com.



Virginia Prostate Cancer Coalition (VPCC)

Officers and Directors:

Chair:

Dick Gillespie PhD

Vice Chair:

Kathy Meade

Treasurer:

John Goulait

Directors:

Alvin Chin

Barbara Dykes

Fred Gersh

Ed Grove

Randy Jones PhD RN

Jim Kearns

Henry Mack

Dick McGrew

Charles Myers MD

Rose Myers PhD

Jim Waldenfels

New NCCN Guidelines Issued

The National Comprehensive Cancer Network (NCCN) has issued new Clinical Practice Guidelines for Prostate Cancer. The guidelines are available at: http://www.nccn.org/professionals/physician_gls/PDF/prostate.pdf The guidelines include new recommendations for active surveillance and the addition of a new “very low risk” category. NCCN is a not-for-profit alliance of 21 of the world’s leading cancer centers, including Johns Hopkins, Duke, and Sloan-Kettering.

New Support Group

Cancer Center at Lake Manassas:

The Cancer Center at Lake Manassas has started a Men’s Cancer Support Group, which will meet the 4th Thursday of every month from 4:30pm-5:30pm, in the conference room at The Cancer Center, beginning January 28, 2010. This group is designed for men coping with prostate and other male cancer diagnoses. Speakers from the surrounding medical communities and cancer survivors with pertinent information to share will be participating on a regular basis and helping participants cope with the specific issues men face with cancer diagnoses. The group is facilitated by a trained and experienced health care facilitator and patient advocate and focuses on empowering men to cope effectively with the challenges of cancer and to find ways to continue enjoying life, health, work, hobbies and relationships. For information, call Robyn Hall-Phelps, The Cancer Center at Lake Manassas, 703-895-4857, or visit www.cancercenterlm.org/PatientInfo/SupportGroups.aspx

Update - Congressionally Directed Medical Research Program

The Congressionally Directed Medical Research Program includes funding for research on prostate cancer. For 2009, Congress made \$80 million available for prostate cancer research. The Department of Defense, through the U.S. Army Medical Research and Material Command, manages the program and utilizes consumers to help select the best research proposals. In 2009, VPCC Board members Dick McGrew and Jim Kearns and UsTOO members Ray Walsh and Bill Bright, also from Virginia, served on Peer Review panels reviewing the many proposals submitted. VPCC Board members Alvin Chin and Dick Gillespie also worked for the second year on the Programmatic Review panels which performed the final review of the 161 proposals selected for funding. Alvin, we are proud to report, continues for his second year as one of the four consumer advocates that sit with twelve medical doctors and researchers on the Integration Committee, which develops policy for this important program." A list of 2009 proposals recommended for funding is listed at cdmnp.army.mil/pcrp/awards.htm. Once the awards are finalized, readers may obtain details at cdmnp.army.mil/search.aspx

Chairman’s comments: While we applaud the 161 proposals and the work our VPPC members performed, this program was initially funded at a higher level, but was subsequently reduced to \$80 million annually, and needs a \$45 million increase to \$125 million, to accelerate the potential life-saving science it supports.

Since its introduction in 1997-98, the prostate cancer program has trained hundreds of young investigators in the field of prostate cancer research, supported and accelerated research on new diagnostic and prognostic tests, and stimulated development of a major new network of institutions that collaborate on clinical trials of new treatments. Despite support from 49 representatives and 22 senators, our request, in concert with 14 other prostate cancer advocacy groups, to increase prostate cancer research funding to \$125 million for FY 2010 was not successful. Clearly, we in the Coalition must come up with smarter and more vigorous advocacy, in concert with other prostate cancer organizations, to increase funding.

Virginia Prostate Cancer Coalition (VPCC)

www.vapcacoalition.org

703-339-0508

A Friend Remembers VPCC

On February 1, 2009, a friend of VPCC, Charlie Brown of Lake Ridge in Prince William County died after a valiant fight against prostate cancer. Charlie followed our VPCC newsletters and web site and supported our efforts to fight prostate cancer. Charlie also was an active member of the Westminster at Lake Ridge UsTOO group and was always engaged in learning more about prostate cancer and sharing that knowledge with others.

VPCC recently received word that Charlie remembered VPCC in his will with a significant bequest. VPCC will use Charlie's bequest to continue our work to make prostate cancer history in Virginia.

Thank you, Charlie and family.



Charlie Brown loved fishing. The picture above captures his spirit.

The Life-Saving Benefits of PSA Screening

The following is an article by Dr. William J. Catalona in the QUEST Winter 2009 Newsletter, available at www.drcatalona.com/quest.asp

I Recommend PSA Screening

I continue to recommend PSA screening to my patients. PSA testing provides the best estimate of risk for having prostate cancer and the greatest chance of avoiding death from this disease.

PSA screening has been widely accepted in the United States and many other countries because it works.

Patients and physicians who are concerned about decreasing the death rate from prostate cancer have relied upon the test because it gives them valuable information and because death rates have continued to fall during the PSA era.

Although the PSA test is not perfect, it is effective in identifying men at high risk for prostate cancer and for detecting it early. Moreover, a strong correlation exists between PSA and aggressive forms of the disease.

Decrease in Advanced Stage Diagnosis

During the PSA screening era in the U.S., there has been an 85% decrease in the percentage of prostate cancer cases that present with advanced-stage disease and a 40% reduction in the age-specific prostate cancer mortality rate.

Similar trends have been reported from the World Health Organization Database in countries that have adopted PSA screening but not in those that have not. These impressive trends would not have occurred if screening detected only harmless cancers.

Screening Makes Treatment More Effective

Early detection would be useless without effective treatment.

The most effective curative treatment, radical prostatectomy, was available before the PSA era, but this treatment didn't show falling death rates until PSA testing was implemented.

Curative treatments are effective mainly in patients with early disease, which is why the most important factor responsible for the falling death rates is PSA screening.

Cure Is the Goal

The physician's job is to ensure that patients receive effective, high-quality treatment to maximize cure rates and minimize side effects.

Goal of Screening

The goal of screening is to detect cancers that could cause suffering and death, but screening may also detect cancers that would never cause symptoms. Currently, because of limited ability to distinguish between harmless and lethal cancers, most cancers are treated.

Over-diagnosis Is Minimal and Inevitable

Some "over-diagnosis" and "overtreatment" will occur with early detection screening, but research on my 5,000+ patients shows it is minimal compared to the "underdiagnosis" of prostate cancer.

To date, no validated test is superior to PSA as a screening device. There is always hope that the PSA test, itself, may be further refined or some other test discovered that would be even more precise. The intelligent use of such tests could certainly diminish, but never completely eliminate, some over-diagnosis and over-treatment.

Presently, no one is able to predict the aggressive or non-aggressive traits of diagnosed prostate cancer. Which patients or doctors would choose to play a game of Russian Roulette with the diagnosis of prostate cancer when so many men die from it?

Under-diagnosis Needs More Attention

“Under-diagnosis” and “under-treatment” are important concerns that have received much less attention than “overdiagnosis,” even though they have life-threatening consequences.

“Under-diagnosis” and “under-treatment” occur when prostate cancer is not detected until it has spread beyond the prostate and when that unnecessary delay in treatment prevents a cure that would have been the result of earlier treatment.

Research on my 5,000+ patients shows “underdiagnosis” is more of a concern than “over-diagnosis.”

Concern Over Active Surveillance

Active surveillance and focal therapy have emerged as strategies to guard against over-treatment; however, physicians should be careful not to throw out the baby with the bath water.

With active surveillance (also known as “watchful waiting”) or focal therapy (also known as “the male lumpectomy”), potentially life-saving treatment may be delayed in patients with initially under-graded or understaged tumors. Some will slip through the cracks and have unnecessary suffering and death from prostate cancer.

Calendar of Upcoming Events

WHO	WHAT	WHEN ↓	WHERE
UsTOO, Westminster at Lake Ridge	Advanced & Recurrent Prostate Cancer monthly meeting discussing prostate cancer issues	Tuesday, January 12 11:00 AM	Westminster at Lake Ridge, 2085 Steeple Place, Lake Ridge, VA 22192, Dick Gillespie; 703-497-0628, Chesterii@aol.com
UsTOO/Man to Man, Fairfax INOVA	Update on National Prostate Cancer Conference in Los Angeles, 2009 Jim Waldenfels reporting	Tuesday, January 12 7:30 PM	Life With Cancer building, 8411 Pennell St, Falls Church. Ed Grove: 703-533-8334 eddyout@verizon.net
UsTOO, Westminster at Lake Ridge	“Prostate Cancer Issues.” Physicians Panel, including, Pratik Desai MD, Urologic Oncologist, Potomac Hospital, and Samir Kanani MD, Radiation Oncologist, Inova Fairfax Hospital	Saturday, January 16 9:30 AM to Noon	Westminster at Lake Ridge, 12191 Clipper Drive, Lake Ridge, VA 22192, Dick Gillespie; 703-497-0628. Free heart healthy buffet!
Us TOO, Richmond	“Experience treating prostate cancer and life style modification.” Elwood Boone MD	Thursday, January 21 7 PM	Auxiliary Bldg, Ridge Baptist Church. Please use side door off parking lot on 1515 East Ridge Rd. near Regency Mall. Peter Moon, 804-346-4407 (evenings)
Cancer Center at Lake Manassas	Issues men face with cancer diagnoses	Thursday, January 28 4:30 – 5:30 PM	Cancer Center at Lake Manassas, 7901 Lake Manassas Dr, Gainesville VA 20155, Robyn Hall-Phelps, 703-895-4857
UsTOO, Westminster at Lake Ridge	Advanced & Recurrent Prostate Cancer monthly meeting discussing prostate cancer issues	Tuesday, February 9 11:00 AM	Westminster at Lake Ridge, 2085 Steeple Place, Lake Ridge, VA 22192, Dick Gillespie; 703-497-0628, Chesterii@aol.com
UsTOO/Man to Man, Fairfax INOVA	“Living with Recurrence” presented by a support group panel	Tuesday, February 9 7:30 PM	Life With Cancer building, 8411 Pennell St, Falls Church. Ed Grove: 703-533-8334 eddyout@erols.com
UsTOO/Man to Man, Fairfax INOVA	“Urinary Incontinence & Treatment” B.J Czarapata CRNP, CUNP	Tuesday, March 9 7:30 PM	Life With Cancer building, 8411 Pennell St, Falls Church. Ed Grove: 703-533-8334 eddyout@erols.com
UsTOO, Westminster at Lake Ridge	Advanced & Recurrent Prostate Cancer monthly meeting discussing prostate cancer issues	Tuesday, March 9 11:00 AM	Westminster at Lake Ridge, 2085 Steeple Place, Lake Ridge, VA 22192, Dick Gillespie; 703-497-0628, Chesterii@aol.com

Visit <http://www.vapcoalition.org/Calendar.htm> for updates to the calendar of events.
Support group leaders may e-mail event information to Carol Noggle at cnogg@comcast.net

*Comments on this newsletter or suggestions for future issues?
E-mail Jim Kearns, Editor, at jkearnsjr@verizon.net*

Virginia Prostate Cancer Coalition
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Lake Ridge VA 22192



Included in this issue:

- *VPCC at Work*
- *Provenge Availability*
- *Active Surveillance (Part 2)*
- *Update on CDMRP*
- *New NCCN Clinical Guidelines*
- *A Friend Remembers VPCC*
- *PSA Screening*

The Virginia Prostate Cancer Coalition

Making Prostate Cancer History in Virginia

LETTER FROM PATRICK C. WALSH, MD:

Prostate Cancer Testing Is Best Option for Men



Until an alternative exists, prostate cancer testing is the best option we have to allow men to make an informed decision. Disparaging testing does a great disservice. Because prostate cancer produces no symptoms until it's too far advanced to cure, as appropriate, men should have a PSA test and examination.

In 1990, before PSA testing, only 68% of newly diagnosed men had localized cancer and 21% were metastatic.

Today, 91% are diagnosed with localized disease and only 4% have metastases.

With the ability to diagnose cancer earlier and treatment advances, U.S. deaths from prostate cancer have fallen 40% in ten years, a greater decline than for any other cancer.

Today, men have a choice that once did not exist: Undergo testing and, if there is cancer, make an informed choice for treatment or observation, or do nothing and run the risk of a diagnosis until it's too late.

I choose to know.

**Patrick C. Walsh, M.D. is the University Distinguished Service Professor of Urology at the James Buchanan Brady Urological Institute, Johns Hopkins Medical Institutions*

Reprinted from QUEST Winter 2009 Newsletter - www.drcatalona.com/quest.asp
