// VIRGINIA PROSTATE CANCER COALITION

Volume 5, Issue 1 Making Prostate Cancer History in Virginia Winter 2011

Chairman's Corner

Dick Gillespie

Much positive is happening in prostate cancer research today! This is underscored in several articles in the Prostate Cancer Research Institute's August 2010 Insights magazine. Drawing on the experience with Proscar (Finasteride) and Avodart (Dutasteride), Dr Paul Schellhammer argues that "programs to promote screening/early detection should be coupled to a strategy of chemo prevention."

Dr. Oliver Sartor's report on the recent FDA approval of cabazitaxel (jevtana) to treat patients with advanced prostate disease offers optimism. Sartor congratulates the FDA for its approval of this drug only 78 days after receiving information from drug manufacturer Sanofi-Aventis. Cabazitaxel, Sartor concludes, "…is the first and only agent to be FDA approved for patients with progressive prostate cancer despite prior Docetaxel treatments."

Dr. Evan Slater's update on options after docetaxel, concludes that this drug has "…unlocked a tidal wave of investigation into multiple targeted, immune based and even hormonal therapy..." Much remains to be probed with today's medical advances, but the future looks to see an accelerated scientific progress in new agents and drugs!

Physicians Ralph Plum and Mark Scholz conclude that those men who start Testosterone Inactivating Pharmaceuticals (TIP), another new form of treatment, before the onset of bone metastasis, respond for more that 10 years before developing resistance to TIP.

After attending a recent Centers for Medicare and Medicaid Services (CMS) meeting in Baltimore with Board members Kathy Meade and John Goulait, I came away somewhat puzzled why they are independently examining the latest therapeutic drug Provenge which the FDA has already approved. While Dendreon's charge for using its vaccine, $93,000-103,000, is high, Medicare now covers the costs of more expensive treatments. CMS's approval of Provenge for "on-label" hopefully removes one obstacle to an early decision as whether the cost of this treatment will actually be covered by Medicare.

The Fall is always a season in which there is an overwhelming series of outreach events in which our Coalition plays important, or pivotal roles. Early on, we got Governor McDonnell to declare September as Prostate Cancer Awareness month.

We spent much time during September contacting Virginia medical facilities about the need for free prostate cancer screening, coming away pleasantly surprised to find a number of organizations actually did provided PSA tests and Digital Rectal Exams.

The Virginia Cancer Prevention Action Plan is now off the ground and running, with several Coalition members playing important roles as members of the Cancer Prevention Action Coalition (CPAC) which is dedicated to ensuring the campaign's success.

In this issue, we thank the many VPCC volunteers at the Virginia State Fair who distributed prostate cancer materials to hundreds of individuals from numerous counties.

Be sure to read the article in this issue on how VPCC struck back at prostate cancer at our booth at the Marine Corps Marathon Expo, where some 10,000 attendees were exposed to our materials. Meanwhile, volunteers also made presentations to various civic and religious organizations and participated in hospital and other locally sponsored health fairs in Richmond, Hampton, and other locales.

In 2011, we plan to emphasize outreach to service organizations, such as Rotary Clubs, and to prostate cancer support groups around the state. We want to get to know these organizations better and work more closely together. We also hope to come away with more volunteers for VPCC programs -- a continuing need.

Thank You to the Volunteers at the State Fair

During the Virginia Sate Fair, many volunteers staffed the VPCC booth. Our volunteers spoke, and provided literature, about Prostate Cancer to hundreds of visitors. In addition to Carol Noggle, who coordinated VPCC's presence at the Stare Fair, the following volunteered their time:

Denny and Wanda Arner, Doug and Mary Camp, Dave and Mary Dallas, John DePerrro, Dick Gillespie, John Goulait, Jim Hanifer, Steve Hornstein, Dick and JoAnn McGrew, Kathy Meade, Peter Moon, Tom Morris, Jerry Mullen, Don Scheu, Steve and Debbie Vasquez, and Solomon Wilson.

Thank you all!!

Active Surveillance – Triggers for Moving to Treatment

This is the fourth in a series of articles on Active Surveillance. The first three parts are available in the newsletters section on www.vapcacoalition.org.

Jim Waldenfels

For the past half decade, study after study at major centers has reported the success of their active surveillance (AS) programs for men with low-risk prostate cancer, and every year additional favorable studies accumulate. In the last two years major, highly respected medical organizations, including the American Urological Association and the National Comprehensive Cancer Network, have come out with guidelines favoring AS as either a prime option or the best choice for low- and very low-risk patients. The emergence of AS has been described in previous VPCC newsletters, but evidence continues to grow that AS is capturing the imagination and hopes of low-risk patients interested in avoiding side effects from radiation or surgery - treatments with a strong likelihood of being unnecessary. In fact as the New Year turned, John Bertrand, the famous Australian yachtsman who snatched away the America's Cup, announced he had prostate cancer and had chosen AS.

However, a key feature of AS is making a timely course change to having curative therapy if diligent surveillance reveals cancer that has become more aggressive than was apparent during previous monitoring. John Bertrand and all men on AS want to have the best possible guidance on whether to remain on AS or move to treatment. While there is not unanimity in expert opinion, there is broad agreement on key features and continuing research to improve the decision process. Here are the basic principles.

Perhaps most important are the biopsy results in the first and second year following the original biopsy used for diagnosis. If either indicates a higher Gleason score, or clearly more extensive cancer, the doctors will recommend treatment. Some centers, especially Johns Hopkins, require their AS patients to have a biopsy every year.

Another key criterion is an unacceptable PSA doubling time, or PSA velocity. While some AS patients have a PSA that doubles only every 100 *years* or more, a PSA increase of 1.0 in a year for an AS patient, who had a fairly low PSA to start with, is a trigger for concern. However, as Laurence Klotz, MD, and colleagues have observed, AS patients are subject to the same infections as those who do not have prostate cancer, and those infections can drive hefty and rapid increases in PSA. The point is that the increase needs to be considered in the contexts of, first, several, spaced tests, ideally over 18 months, and, second, of the possibility of infection and other causes of PSA elevation.

Dr. Klotz's longest running, large and well-reported series in Toronto, with more than 450 AS patients since 1995, features regular DRE exams in addition to PSAs and biopsies. In addition to an increase in Gleason to 4+3=7 or higher, or a PSA doubling time of less than three years, or unequivocal clinical progression as triggers for switching to treatment, his team is exploring emerging technologies, including dynamic contrast-enhanced and diffusion weighted MRI, PCA-3, and other tests including Aureon, Mitomics, and SNP gene mutation analysis. The well-known medical oncologist Mark Scholz, in his recent book, "Invasion of the Prostate Snatchers," uses additional tools including a color Doppler ultrasound semiannually and a spectrographic endorectal MRI annually, allowing comparisons with baseline images for revealing growth, with the PCA-3 repeated every six to twelve months. Dr. Snuffy Myers uses similar tools, including color Doppler, but also including dynamic enhanced endorectal MRI, which captures blood flow like color Doppler. Each major center has its own mix of clues for triggering treatment. These have been mentioned in reports from Toronto, Johns Hopkins, Memorial Sloan Kettering, MD Anderson, UCSF, and the Erasmus Medical Center in the Netherlands.

While as of 2011 the ideal combination of triggers for moving from AS to therapy is still being debated, perhaps the vital key is diligent monitoring with tools now available for AS. As Dr. Myers has emphasized, properly done AS is very effective, but neglecting monitoring can be tragic.

Since AS requires a disciplined regimen of frequent PSA tests, annual biopsies, modification in diet/life style, and other requirements a physician might prescribe, patients should consider whether or not they have the patience and commitment to undergo this treatment long term.

If you are receiving this Newsletter via snail mail, please let us provide the newsletter to you via e-mail. You get it faster and in color. VPCC saves printing and postage costs. Provide your e-mail address to Jim Kearns, Editor, at info@vapcacoalition.org

Malecare Advanced Prostate Cancer Program

Malecare has enhanced its Advanced Prostate Cancer Program with a new set of Prostate Cancer Kits. Their first kit is focused on helping men who have already survived their initial diagnosis and are now dealing with recurrent disease, including a new, easy to read guide on how to understand and navigate living with recurrent prostate cancer. For more information and to obtain a "Recurrent Prostate Cancer Book," visit http://malecare.org and, at the top of the page, click on "Advanced and Recurrent Prostate Cancer Program." Malecare's phone number is 212-673-4920.

VPCC Strikes Back at Prostate Cancer

How many of us, once we have learned that prostate cancer has us in its cross hairs, feel that strong urge to strike back at the cancer, to avenge the insult to our well being, to our families, and to our lives? Most of us in the Virginia Prostate Cancer Coalition, and readers of this newsletter, have probably had that feeling. Well, thanks to your support of the coalition, we have struck back!

For the past six years VPCC, teaming with the Foundation for Research and Education (FCRE), have rented and manned a booth at the Marine Corps Marathon Health & Fitness Expo, held annually during late October in Washington, DC, in the days before the race. Volunteers have hauled our materials, posters and banners to the sites, set up the booths, and then handed out materials to thousands of attendees, as well as answering questions from those who wanted more information. This Expo "audience" has proven ideal for the VPCC and FCRE as it consists of many thousands of men and women interested in health who are at an age where prevention and early detection can make a key difference.

Our materials are aimed mainly at prevention for this group, though we have also offer information on screening, treatment, support, and other key topics. We primarily use FCRE's eye-catching and informative cards and pamphlets on nutrition, supplements, diet, exercise and other lifestyle tactics that appear to lower the risk of getting prostate cancer or having higher risk disease. These tactics feature high "therapeutic index" actions - actions with evidence of effectiveness but with very low risk - that are easy to do, such as getting adequate vitamin D, eliminating red meat, increasing lycopene in the diet, substituting healthy fats - such as olive oil and fish oil - for unhealthy fats, and exercising.

The Expo is an exceptionally high volume event, with approximately 100,000 attendees. A substantial proportion of them are from Virginia, where much of the marathon race takes place, but the DC Metro area, many states, and a number of countries are also represented. In 2010 our dedicated team of volunteers surpassed our previous marks, passing out information to 4,790 attendees. As many couples, families, and small groups received one set of handouts, it's likely that 10,000 saw our helpful information. Even the attendees striding quickly past the booth without accepting our pamphlets heard and saw our message that there are ways to help prevent prostate cancer, so we planted the seed idea of prevention in many more minds. The event has also proved a superb venue for communicating with African Americans, a group that is at high risk but often hard to reach; at least 511 African Americans received information in 2010. Based on our success, for the first time this year VPCC and FCRE staffed a booth at the Historic Half Marathon in Fredericksburg, which also proved to be a most worthwhile event.

If you would like to support this initiative, please donate to VPCC and FCRE, or volunteer. Our booth at annual State Fair offers a similar opportunity.

Help VPCC!!
Please donate and help continue to fight prostate cancer. Go to www.vapcacoalition.org and click 'Donate.'
We acknowledge all donations.

Clinical Trials 101+

The Virginia Cancer Plan Action Coalition (CPAC) is sponsoring a workshop "Clinical Trial 101+," intended dispelling myths, breaking down barriers, stimulating community engagement in research, and promoting inquiry about trials. The free workshop will take place on Thursday, March 10th, from 9 AM to 1 PM and will be broadcast to the following locations: Abington, Big Stone Gap, Danville, Fairfax, Lynchburg, Newport News, Norfolk, and Richmond. For more information, call Ann Duesing on 276-328-0168.

Meet Your VPCC Volunteers

Dick McGrew lives in Williamsburg with his wife, JoAnn. Before he retired in 2003, Dick served as the Chief of Police for the College of William and Mary. For VPCC, Dick assists with health fairs and the state fair. Dick also makes presentations on Prostate Cancer to civic and church groups in the Williamsburg and Richmond areas. When not supporting VPCC, Dick finds time to kayak, bike, refinish furniture, and volunteer with Meals on Wheels and the Tidewater Chapter of the Appalachian Trail Club. Thank you, Dick!

Comments on this Newsletter or suggestions for future issues? E-mail Jim Kearns, Editor, at info@vapcacoalition.org

Virginia Prostate Cancer Coalition
2085 Steeple Place
Lake Ridge VA 22192

In this issue:

- Thank You Volunteers at the State Fair

- Active Surveillance - Triggers

- Malecare Advanced Prostate Cancer Program

- VPCC Strikes Back at Prostate Cancer

- Clinical Trials 101+

- Meet Your VPCC Volunteers

Co-Pay Relief Program

The Patient Advocate Foundation (PAF), a national non-profit has announced that it has received a substantial contribution which will provide additional funding support for prostate cancer patients through its Co-Pay Relief Program (CPR).

PAF's Co-Pay Relief Program provides direct financial support for pharmaceutical co-payments to insured patients, including Medicare Part D beneficiaries, in 20 disease categories.

Since the program's inception in April 2004, CPR has distributed more than $77,650,000.00 million in assistance to over 36,000 men. In the last year, several internal enhancements have been made to the Co-Pay Relief Program to improve access including raising federal poverty (FPL) guidelines from 250% to 500% and creating 24-hour provider application portal.

"We are thrilled to announce additional funding for prostate cancer patients, which will allow us to offer financial assistance to hundreds of additional patients each year. The program is designed to improving the quality of life of men facing medical and financial hardship.

Nancy Davenport-Ennis, Founder and CEO of PAF said, "A cancer diagnosis can be the most overwhelming experience a person may ever face in his or her lifetime. Coupled with high out of pocket costs associated with treatments and therapies, the journey can become significantly more challenging to manage - so we are particularly pleased to be able to offer assistance to so many more men, which will lead to more thorough management of their disease."

For more information about PAF's Co-Pay Relief Program visit www.copays.org or call toll free 866- 512-3861.

Virginia Prostate Cancer Coalition (VPCC)
www.vapcacoalition.org
703-339-0508