

## Save The Date

### September 14

The KnowledgeNet "In The Know" Awards Luncheon  
New York, NY

Details at:

[www.theknowledgenet.info](http://www.theknowledgenet.info) or  
1.888.477.6763

### September 20

CancerCare Telephone Workshop  
Better Bone Health for Men  
Living with Prostate Cancer  
Register at: [www.cancercare.org](http://www.cancercare.org)  
or 1.800.813.HOPE

### September 24

APCaP Run-Walk New Jersey  
Duke Island Park  
Bridgewater, NJ

### October 4 – 6

Third Biennial Cancer  
Survivorship Research  
Conference  
Bethesda, MD  
Details at: [www.blsm meetings.net/  
survivorship06](http://www.blsm meetings.net/survivorship06)

### October 14 – 16

1st Barbers International  
Conference  
Las Vegas, NV  
Details at:  
[www.barbersinternational.com](http://www.barbersinternational.com)  
or 1.866.698.6463

### October 27 – 30

Society of Urologic Nurses and  
Associates Annual Conference  
Details at: [www.suna.org](http://www.suna.org) or  
1.888.827.7862

### February 22 – 24, 2007

The Prostate Cancer Symposium  
Orlando, FL  
Details at: [www.asco.org](http://www.asco.org)

### August 27 – 31, 2008

UICC World Cancer Congress  
Geneva, Switzerland  
Details at:  
[www.uicc.org/congress08](http://www.uicc.org/congress08)



## DRUGS USED TO TREAT BPH MAY ALSO PREVENT PROSTATE CANCER

by Diane Johnson

New evidence shows that doxazosin and terazosin (alpha-blockers), currently being used for the treatment of BPH (Benign Prostatic Hyperplasia) and hypertension, may also decrease the risk of developing prostate cancer. In addition, they may prevent the progression to advanced prostate disease if the PSA begins to rise after initial treatment.



Natasha Kyprianou, MD, PhD

The study was conducted at the University of Kentucky Medical Center by a research team led by Natasha Kyprianou, MD, PhD, Professor of Urologic Surgery and Director of Urologic Research at the Markey Cancer Center. Dr. Kyprianou and her colleagues presented the results of this retrospective study at the annual meeting of the American Urological Association in Atlanta in May. Doxazosin (brand name: Cardura) and terazosin (brand name: Hytrin) are widely used for the treatment of the various obstructive symptoms of BPH (enlarged prostate, difficult or painful urination, etc.). They work by relaxing the muscles of the bladder and prostate. Growing evidence suggests that these drugs have additional effects such as targeting prostate growth by inducing cell death (apoptosis) and reducing tissue vascularity (angiogenesis) in both the benign and the malignant prostate.

The researchers analyzed the medical records of over 27,000 male patients from the Lexington Veterans Administration Medical Center in Kentucky who were treated with these blockers for either hypertension or BPH between 1998 and 2002. These data were then linked with prostate cancer diagnoses found in the Kentucky Cancer Registry, a National Cancer Institute's central cancer registry. Dr. Kyprianou and her colleagues found that men who took the blockers had a 40% lower risk of developing prostate cancer than men who did not receive those drugs.

Longer term, prospective, randomized trials are needed to test doxazosin and terazosin before they can be recommended for use as prostate cancer chemopreventive agents. Such studies might be aided by the fact that these drugs are FDA-approved, have an established safety profile (meaning they are generally well-tolerated), and are already being used by a large number of men. "I recognize that this initial retrospective study has certain limitations, such as our inability to adjust for age," Dr. Kyprianou says.

"However this is exciting epidemiological evidence linking for the first time the molecular effects of alpha-blockers in inhibiting prostate growth to a potentially significant role of these medications in preventing prostate cancer development and progression to advanced disease."

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After two years of an intense work schedule and family issues, I was finally able this past April to take a combination vacation, birthday and anniversary week in Europe. Naturally, in the spirit of “No good deed goes unpunished”, I immediately came down with a respiratory infection as soon as I got off the plane, which threatened to compromise the pleasure I was anticipating.



My wife suggested that I call back to New York to get a prescription from my doctor; however, I then remembered that the system in Europe (and Mexico) is different from the U.S. – I didn’t need a prescription to get the same antibiotic; I just had to go into the drugstore and ask the pharmacist for what I needed; and if I didn’t know what to ask for, a conversation with the pharmacist would get it for me!

The experience caused me to reflect on the process that would have been

necessary back home: make an appointment with my doctor for an examination, get a prescription, take it to the drug store to be filled, hope that the prescription plan would be accepted by the pharmacy. At best, assuming that I had insurance with reasonable co-pays, I would be absorbing a cost that was comparable to the cost of dinner with wine that I had in Italy after paying for the antibiotic which cost less than the taxi fare to my doctor’s office! Is our system based on meeting patient needs or are there other imperatives in place?

My thoughts then extended to the process of getting new drugs to treat advanced stage disease and how our drug approval procedures often deny access to therapies that might be of benefit to patients. We state that our process insures that those drugs that gain approval have the highest level of safety. I accept that, but are the Governments of Italy or Mexico and others less concerned about the welfare of their citizens; I doubt it. We have a system that demands a drug show benefit in patients at the most extreme stage of progression; yet it might show a greater benefit among patients at earlier disease states, however, as patients, we don’t get to make that choice.

In an environment wherein the patient is encouraged to make “informed decisions” from screening to treatment, why can’t a decision, based on personal risk assessment amidst desire for survival and/or improved quality of life, be offered to the patient and their doctor at an earlier point in the disease management/drug approval process to make an informed choice for life. It’s a question on the minds of many patients and a statement that we need to make a change. ♂

## CORRECTIONS & CLARIFICATIONS

The following relate to the March 2006 issue:

### 1. Virus Found in Rare Form of Prostate Cancer

Dr. Robert Silverman of the Lerner Research Institute is a co-discoverer of the XMRV virus in partnership with Dr. Eric Klein of the Glickman Urologic Institute at the Cleveland Clinic.

### 2. Androgen Deprivation Therapy (ADT)

--The bisphosphonate, Zometa, is approved for use with metastatic disease and is not currently approved for use before mets appear.

--Dr. Michael Carducci was quoted on the current practice relating to ADT. In fact, he was summarizing data from the CaPSURE Consortium.

# LETTER FROM HOME

Here is my story.



By Robert McCoy  
as told to Julia McCoy

I was born and raised in New Orleans, LA. I am 25 years old and have been married for 5 years. I worked for a grocery store warehouse for the last two years before Hurricane Katrina. Early in 2005 I hit myself in the chest with a heavy box at work. That event brought to my attention a small lump in my chest. However, at the time, I thought it was just a bruise. I was assured by all of my co-workers, ages 18 to 80, that it was a normal, work-related injury that they had all experienced before and that it would go away. A little drop of blood would come out of my nipple near the lump every other day or so, but again, my co-workers said this too was normal. So I really didn't worry about it. I was just waiting for it to go away.

On August 28, 2005 my wife and I woke up to a mandatory evacuation for all of South Louisiana including our beloved hometown of New Orleans. We threw a few necessities in the car and headed for my wife's parents' house in North Texas. Because of the traffic, it took us 20 hours to drive what would normally have been an 8 1/2 hour trek. To make matters worse, we started seeing Ku Klux Klan signs after dark. This would have been scary even if we, my wife and I, were not a mixed race couple. The fact that my wife is white and I am black caused me to press my foot on the accelerator as far to the floor as possible. After finally making it to Fort Worth we checked into a hotel. Little did we know we would be living there for two months.

A few days after settling in to the hotel, my wife decided I had better get this lump in my chest checked out because we were losing our jobs and we would be losing our health insurance within a matter of months. I saw a primary care physician, then a radiologist, and then went to a surgeon for a biopsy. Ten days after arriving in Ft. Worth I was diagnosed with male breast cancer, ductal carcinoma in situ. I had a left-side mastectomy on October 14, 2005. During the surgery, they took some of my lymph nodes and fortunately found out that the cancer had not spread beyond my breast. Because my wife and I may one day have children, I underwent genetic testing and found out that I do not have the BrCa1 or BrCa2 gene. When I went to an oncologist for follow-up treatment he gave me a couple of treatment options. To prevent the cancer from coming back he said I could take Tamoxifen for 5 years, which would affect my sex drive and my ability to have children among other things. My second option was to have a right-side mastectomy. I chose the latter and had that surgery on December 21, 2005. Our health insurance ran out 10 days later so I have been going to public clinics for care ever since then. I am feeling better physically than I was right after the surgery, but I still have severe pain in my chest that comes from out of nowhere sometimes. I was recently diagnosed with hypertension, which the nurse at the clinic said was no surprise considering everything that I've been through.

I lived across the street from my parents and my little brother in New Orleans. During this whole ordeal I saw my mother only once. I did not see my dad or little brother at all until February 2006. I have hardly seen any of my friends since the storm. Some people say that depression is not real, and that we should all just get over Katrina and move on with our lives. But I have dreams every night about home and I wake up every morning very sad. About two weeks after my first surgery the city government assisted us in finding an apartment in East Fort Worth. It's nice to be in a real home again. Even if it's not in my once-beautiful New Orleans, my wife and I do everything we can to make wherever we are feel like home.

My faith in my God Jehovah, the support of my strong and loving wife, and my refusal to feel sorry for myself have helped me to get through this trying ordeal. In addition, I have been giving interviews and trying to get the word out about breast cancer, especially among men, and that has helped me in the healing process as well. As you know, men DO get breast cancer, but it is never YOUNG men. Also, I have no history of cancer in my family for over 3 generations. I would like to get the word out that if there is something unusual going on with your body, you need to have it checked out. No matter who says it is normal, if it is not normal for you, get it checked out. ♂

## Medical News Highlights

**Amgen** reported positive results for their drug, **Denosumab**, in improving bone density in oncological therapy situations. They have opened up three Phase III trials in Prostate Cancer, Breast Cancer and Solid Tumors targeting skeletal-related events.

-Medical News Highlight

Results from the **ASCENT** (AIPC Study of Calcitriol Enhancing Taxotere) study at the Oregon Health & Science University Cancer Institute showed that patients with advanced prostate cancer could be treated successfully with intermittent chemotherapy. Current practice standards require that patients take chemotherapy for a fixed period or until the disease progresses or until the side effects become intolerable. Of the test group more than 75% responded positively to the chemotherapy after a "holiday" from treatment.

-Medical News Net

**Lilly Icos** will be running trials of its impotence drug, **Cialis**, as a potential treatment for enlarged prostate and hypertension; preliminary results are expected sometime later this year.

-Seattle Times

**GTx**, according to an article in The Commercial Appeal, is banking heavily on several clinical trials currently on-going worldwide to give it some cash influx to enable it to continue on the drug approval process. Two Phase III trials of the prostate cancer drug, **Acapodene**, are on-going: one involving 1400 people in Argentina, Canada and the U.S. is determining if the drug can prevent precancerous lesions from developing into prostate cancer; the second, made up of 1400 patients in Mexico and the U.S., will determine if the drug can reduce side effects associated with chemical castration.

Researchers at UCLA's Jonsson Cancer Center reported on a study that showed that pomegranate juice slowed the PSA doubling time of patients with recurring prostate cancer after primary therapy surgery or radiation. It's theorized that the antioxidative effect of **pomegranate juice** acts on the inflammation factors associated with prostate cancer.

## Medical News Highlights

**Traysol**, (chemical name – aprotinin) a drug used to reduce blood loss in patients undergoing heart-bypass surgery, has been found to cause serious side effects as reported in an article in the New England Journal of Medicine. A study done by researchers at the Multicenter Study of Perioperative Ischemia Research Group and the Ischemia Research and Education Foundation found increased incidence of required kidney dialysis, myocardial infarction and heart failure among the patient population analyzed. Details can be seen at:

<http://content.nejm.org/cgi/content/short/354/4/353>

In another article from the New England Journal of Medicine - <http://content.nejm.org/cgi/content/short/354/4/333> - research showed that African-American and Native Hawaiian smokers were more likely to develop lung cancer than whites, Japanese-Americans and Latinos. While seemingly critical, dissenting editorial opinion suggested that “eliminating smoking would largely reduce and equalize the rates of lung cancer” across all groups.

In a study at the University of Chicago, it was found that the use of a **robotic system in prostate surgery** enabled obese patients to achieve comparable post-surgical results to men who were overweight or had normal body mass indices. Their regain of urinary continence and sexual function did not differ significantly from the other groups despite the fact the procedure on obese patients took about an hour longer and had a higher blood loss. The implication is positive for men who were not usually considered candidates for prostate surgery.

*-Urology, April 2006*

Obesity has been linked to the likelihood of treatment failure after radiation therapy as detailed in the journal **Cancer** reporting on a study of 295 men at the M. D. Anderson Cancer Center.

*-Cancer, August 1 2006*

**Isis Pharmaceuticals** has started clinical trials with **Eli Lilly** of an anti-cancer drug called LY2275796 that targets a protein called eIF-4E that is found in higher concentrations in breast, prostate, lung and other cancers.

*-North County Times*

# ADVOCATES & THE NCI-BUILDING A BRIDGE

By Diane Johnson

To most of us, the institutions of the National Cancer Institute (NCI) and the National Institutes of Health (NIH) seem massive and unapproachable. To begin to remedy that, the NCI hosted the first summit for cancer advocates in Bethesda, MD in June. **Listening and Learning Together: Building a Bridge of Trust**, brought together over 250 representatives of cancer advocacy organizations from all over the country and key representatives from the NCI and NIH to discuss issues and needs in the cancer community, share resources and innovations from other advocacy organizations and the NCI, and, most importantly, to initiate dialogue.

The summit was planned by the Director's Consumer Liaison Group (DCLG) of the NCI. The DCLG was formed in 1997 as the first all-consumer advisory group at the NIH. Its mission is to "establish and maintain strong collaborations between the NCI and the cancer advocacy community" in order to ensure that those who are affected by cancer have a voice in shaping policies and goals. The panel is a diverse group of cancer advocates, survivors, family members, and health care professionals who make recommendations to the Director of the NCI.



*Dr. John E. Niederhuber*

Acting Director, Dr. John E. Niederhuber opened the conference with a presentation titled "Frontiers in Cancer Science". He focused on three areas of future research and cancer biology:

### Tumor Microenvironment

Cancer is a complex systemic "disease of the genome" caused by changes in cell DNA over time. Instead of independent cell masses, tumors are now seen as "organs" with their own blood supply and biochemical support systems. The old approach of "search and destroy" has been modified to "target and control". The goal is to pre-empt the developing cancer before it turns deadly and keep it from progressing.

### Cancer Stem Cells

The mutations that lead to cancer appear to occur only in cells that can regenerate themselves. These stem cells also have the innate ability to travel to other tissues and some are resistant to

chemotherapy. Targeting stem cells for cancer research will provide valuable data on how cancers grow and how to stop them.

### Vaccine Therapy and Cancer Prevention

Finding a vaccine for HPV (Human Papilloma Virus), the cause of 99% of cervical cancer, is a stunning development. Prevention of cancer is, of course, still the ultimate goal. "Predictive medicine" could assess each person's potential risk of disease development and indicate which drugs would interrupt the process. If necessary, treatments could be designed according to each individual's genetic profile.

### Other topics covered at the conference were:

#### Survivorship

With over 1.3 million new cancers and more than one-half million deaths in 2005 alone, the war on cancer that began in earnest in 1971 is clearly not over. But officials estimate that there are over 10 million cancer survivors (3.6% of the population) in the U.S. today. (Three cancers, breast, prostate, and colorectal, account for about 50% of the survivors.) In 1971, less than 50% of people diagnosed with cancer lived for five years. Now the majority do. Cancer has become a chronic disease like diabetes or heart disease for many. Dr. Julia Rowland, from the Office of Cancer Survivorship, noted that early detection, more effective treatments, and better care have contributed to this remarkable progress. In fact, the odds of survival are so much greater now that the field of Cancer Survivorship is growing exponentially. Long-term side effects of treatments, the psychological impact of the cancer process, and lifestyle changes to prevent relapse are just some of the critical concerns of survivorship.

#### Clinical Trials

One area of consensus at the summit was that more emphasis and outreach for clinical trials is necessary. It is no coincidence that 70% of children who have cancer participate in clinical trials

## ADVOCATES & THE NCI-BUILDING A BRIDGE

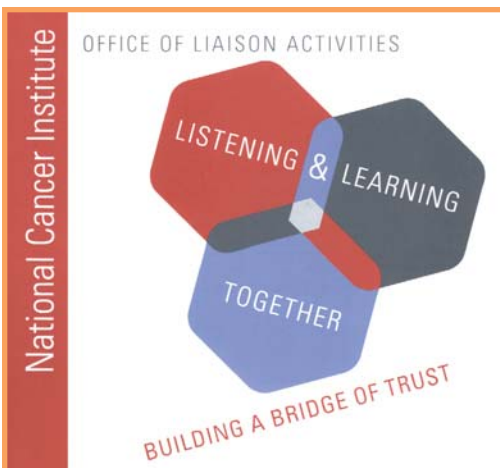
and the combined cure rate for childhood cancers is approximately 80%. Typically, only 3% of adults participate. Until recently, older cancer survivors were not even accepted in clinical trials, but now the barriers are more likely related to a lack of information or access. Many physicians are unaware of trials or how they work as well. There are many initiatives all over the country to demystify the clinical trial process and encourage participants of all ages and ethnicities. Those attending the

summit agreed that we need to work together to explain and promote clinical trial participation.

### Disparities

It is still a fact that minority and rural/underserved populations are at more risk of advanced cancer diagnosis and early mortality. Dr. Niederhuber said that research may yield results that cannot be communicated clearly yet. In addition, he added, "Access may be a greater predictor of mortality than tobacco." A distinguished panel of doctors, lead by Dr. Mark Clanton, Deputy Director of Cancer Care Delivery Systems for the NCI, presented a comprehensive overview of some successful model programs that are addressing healthcare treatment and research in minority and underserved communities:

University of Maryland--study of clinical trial participation barriers and a



statewide health network for community prevention and education.

South Dakota--many programs including study of cancer and chronic disease risk factors and diabetes and tobacco education and prevention projects at the Black Hills Center for American Indian Health.

Cancer Preventorium in Washington, DC--a comprehensive program of information and prevention for Latino families, with a strong media component that focuses on radio.

Delaware Valley--Asian Community Cancer Coalition that uses community outreach, a media campaign, and culturally appropriate materials to educate and motivate Asian-Americans, whose leading cause of death is cancer and whose healthcare is complicated by language barriers.

### Patient Resources

The NCI website, [www.cancer.gov](http://www.cancer.gov), is an invaluable resource for cancer patients and their families, advocates, healthcare workers, and anyone who needs a little or a lot of information about cancer. The following is a partial list of what you can find on the site:

- ♂ Disease-specific information
- ♂ Decision-making aids
- ♂ Dictionary of cancer terms
- ♂ NCI Cancer Bulletin (weekly online newsletter)
- ♂ Caregiver materials
- ♂ Clinical trials information and search
- ♂ Drug dictionary

There is a wealth of publications, many in Spanish, available to anyone free of charge at [www.cancer.gov/publications](http://www.cancer.gov/publications) (there is a small shipping and handling charge for bulk orders). All of the materials and resources are produced by the NCI with a commitment to scientific accuracy and understandability. For those who are looking for more scientific research data, [www.pubmedcentral.com](http://www.pubmedcentral.com) is a free digital repository of life sciences journal articles compiled by the NIH. In addition, the National Library of Medicine is an amazing resource that includes access to the world's largest collection of biomedical literature and access to an inter-library loan network. Access the library at [www.nlm.nih.gov](http://www.nlm.nih.gov) and MEDLINE data, a collection of consumer health information in both English and Spanish, at [www.medlineplus.gov](http://www.medlineplus.gov).

As Dr. Elmer Huerta of the Washington Cancer Institute says, those fighting the on-going war on cancer need to "focus on not only the tumor, but the *person* with the tumor." Those living with cancer everyday and those who have dedicated their lives to fighting cancer everyday must share their resources and their passion to win this battle once and for all. ♂

## Lest We Forget.....

Prostate Cancer Kills!! Although the mortality rate has been decreasing overall, it is still unacceptably high among minorities and the medically underserved. We see too much death every day from those who have written or called for information, or whose families have tried to get the information needed to provide care. There are those who have crossed your path in life who have also succumbed. Let's take a moment to remember some of the more notables who have passed this year:

**Earl Woods** – father of golfer Tiger Woods and a Vietnam Veteran

**Chic Hecht** – former Senator from the State of Nevada

**Lew Anderson** – was Clarabell the Clown on The Howdy Doody Show

**Floyd Patterson** – former heavyweight boxing champion

Early detection can help to save lives; encourage your friends and relatives to become informed about the disease and to see their doctor or medical center to best assess their risk. More than 30,000 men will die this year from prostate cancer; that number **can** be reduced with all of us working together

## Medical News Highlights

**Gleevec**, a drug used to treat chronic myelogenous leukemia and gastrointestinal stromal tumors, has been found to be effective in treating metastatic prostate cancer. A study conducted by The University of Texas M.D. Anderson Cancer Center showed that Gleevec, used in combination with Taxol, killed the blood vessels that provide oxygen and nutrients for the tumor.

- Medical Research News

The U.S. Food and Drug Administration voted to recommend the return of the multiple sclerosis drug, **Tysabri**, to market. Biogen Idec and Elan had previously voluntarily removed the drug after some studies showed a link to a rare brain disorder. Details can be viewed at:

[http://www.bloomberg.com/apps/news?pid=1000102&sid=ay7.hP7L..\\_I0&refer=uk](http://www.bloomberg.com/apps/news?pid=1000102&sid=ay7.hP7L.._I0&refer=uk)

**GTx** reported that it has enrolled over 1,300 patients in a Phase III trial of its drug Acapodene for the treatment of side effects of androgen deprivation therapy (ADT). Additional drugs, **Ostarine** and **Andarine** are also in development to address the effects of wasting resulting from chemotherapy treatment. Additional information can be seen at: <http://www.gtxinc.com/tech/pipeline.htm>

Although the New Drug Application (NDA) for **Xinlay** to be used to treat men with metastatic hormone-refractory prostate cancer was not approved by the FDA, Abbott continues to study the drug's effectiveness via an on-going Phase III study of men with non-metastatic hormone-refractory prostate cancer. Currently Xinlay can only be obtained by individual patients through a Single Patient Investigational Drug (sIND) program through a process initiated by their physician. Details on the program can be obtained from 866.422.8662

Researchers at Cleveland Clinic and the University of California San Francisco have discovered a new virus, **XMRV**, which is 25 times more likely to be found in prostate cancer patients with a specific genetic mutation than men without the mutation. Additional information can be seen at: <http://www.medpagetoday.com/HematologyOncology/ProstateCancer/tb/2741>

## Medical News Highlights

Men undergoing radiation therapy for the treatment of prostate cancer are not at an increased risk to develop rectal cancer versus those not receiving radiation therapy. A study at the Ottawa Hospital Regional Cancer Centre in Ontario, Canada evaluated the records of 237,773 patients with prostate cancer and found no significant increased risk of rectal cancer.

*-Journal of Radiation Oncology-Biology-Physics*

New data published in the British Journal of Urology International confirmed that **bicalutamide** (Casodex) improves the chance of survival by 35% in men with locally advanced (spread outside of the capsule) prostate cancer when given as adjuvant to radiation therapy compared to radiotherapy alone. Details of the report can be seen at: <http://www.medicalnewstoday.com/medicalnews.php?newsid=36938>

**GVAX**, the immunotherapy vaccine, has been shown to have positive results in the treatment of hormone-refractory prostate cancer. Data to date suggests a median survival rate that will exceed the current approved standard of Taxotere (docetaxel) plus prednisone. Two current Phase III clinical trials are enrolling patients for further evaluation. Details can be seen at: <http://www.medicalnewstoday.com/medicalnews.php?newsid=36938>

## New Program Partners

Here are a few of the most recent participants in the program:

**National Association of Barber Boards of America**  
[www.nationalbarberboards.com](http://www.nationalbarberboards.com)

**Fannie E. Rippel Foundation**  
[www.fdncenter.org/grantmaker/rippel](http://www.fdncenter.org/grantmaker/rippel)

**Safe At Home Prostate Awareness Network**  
[www.safe-at-home.net](http://www.safe-at-home.net)

**Gilda's Club**  
[www.gildasclub.org](http://www.gildasclub.org)  
1.888.GILDA-4-U

**CancerCare**  
[www.cancer.org](http://www.cancer.org)  
1.800.813.HOPE

**Barbers International**  
[www.barbersinternational.com](http://www.barbersinternational.com)  
1.866.698.6463

**The Thapelo Institute**  
[www.thapelo.org](http://www.thapelo.org)

**UICC World Cancer Congress**  
[www.uicc.org](http://www.uicc.org)

# BOARD MEMBERS SPOTLIGHT

The Prostate Net/Knowledge Net works to empower our audience through education that leads to informed action. Much of our strength comes from the committed Board of Directors Members who guide our vision. The following is the third in a series of articles that focus on these individuals and the good that they do.

## Board Members | BILLY JAMES PARROTT



*Bill Parrott*

Since the inception of The Prostate Net, Bill Parrott has been the visionary, the big-picture guy. In meetings, he is the one who pushes us to look beyond the ordinary, to set ambitious goals, to look at a problem in an unusual way. That's the nature of a pioneer. They aren't afraid to forge into areas where others haven't been before.

Bill Parrott's career has been marked by vision and firsts. Starting as a mail boy at McCann Erickson, the second largest advertising agency in the world at the time, he became an award-winning copywriter in his first year. Within five years, he had moved to Benton & Bowles agency as Creative Supervisor in charge of accounts like Crest and Post Cereals.

In 1969, he created Parrott & People Communications, a film production company. He wrote and produced documentaries, music videos, commercials, and films. Two of his films were shown on PBS and his television movie based on the childhood of Dr. Martin Luther King, Jr., "The Boy King", won the George Peabody Award for directing. He has worked with many celebrities including Stevie Wonder, Gladys Knight, Herbie Hancock and others.

At the same time, Bill was pioneering in another industry: telecommunications. His company, Private Networks, Inc. (PNI), was instrumental in the development of both the cable and cellular industries. In 1986, his company built a cellular system in Roanoke, Virginia. Two years later, he purchased Coastal Communications, a water-based cellular system located in the Gulf of Mexico. PNI's Satellite Mobile Telephone subsidiary became one of the eight founders of American Mobile Satellite Corporation (now called Motient). He was also a member of the Executive Committee that made the decision to form XM Satellite Radio.

In the non-profit arena, Bill has served on the board of the American Youth Hostels for ten years. We at the Prostate Net are privileged to have him as a member of our board and Director of Programmatic Strategy. We intend to take advantage of his pioneering and visionary skills at every opportunity!



## "In The Know" Multi-Copy Distribution

We have received several requests from patient support groups, community service agencies, barbershops, medical centers and doctors' offices for multiple copies of this newsletter to distribute to their clients or constituents.

If you need more than one copy of each edition of "In The Know", please advise us and we will provide the quantity needed. Send your name, organization name, postal address and email to: [virgil@prostatenet.org](mailto:virgil@prostatenet.org)

# Getting the Drugs We Need

The past three years have been full of contention amongst patient advocates, the Food and Drug Administration (FDA), Congress and pharmaceutical manufacturers over the issue of access to developmental therapies for patients suffering with advanced stage disease. This is of particular concern in the area of prostate cancer in that, while the overall death rate from prostate cancer has declined, the death rate for advanced stage patients and for those men who receive an initial diagnosis at advanced stage has not seen comparable decline.

Recent news stories have spotlighted the efforts of the **Abigail Alliance** (<http://abigail-alliance.org>) to change the FDA's policy of barring the sale of experimental drugs that have not passed the revised approval process, which adds a further level of clinical investigation. This policy, which has been termed "Decelerated Approval Initiative", is being challenged in Federal court by the Abigail Alliance on the basis that critically ill cancer patients should have the right to use drugs that have passed Phase I trials and shown positive benefit case histories in order to make a potentially life-saving personal decision. While not commenting on the specific merits of the lawsuit, many medical practitioners and medical societies, have emphasized that quality cancer care ensures that patients have access to effective therapies through a drug approval process that is safe and expedient.

Under the current regulations approval may be requested after completion of Phase II or Phase III studies. Limited approval may be granted if these trials have shown that the drug has had an impact on an endpoint – survival, lowered toxicity, etc. - that is likely to have benefit for the patient. However, approval under this section requires that further studies continue to determine clinical benefit. It is this extended review process that has become the stuff of controversy.

Should not a patient faced with the prospect of a life-ending disease eventuality be able to decide if they want to use an experimental therapy that could have a positive benefit? When faced with a certain and painful death, why shouldn't the possibility of hope be provided for an informed decision by the patient, his doctor and family caregivers. I think back on a movie titled "Whose Life Is It Anyway?"; most patients will vehemently assert, "It's Mine!!!" If we promote making informed decisions on whether or not to screen, whether surgery or radiation is better, then why not on whether or not we want to take the risk to extend our lives. It is still our life and not the Government's!

**WE WANT TO HEAR FROM YOU!**

To better serve our readers, we need to know what you think of this publication.

Call our **"Hotline" 1-888-477-6763** and give us answers to the following questions:

- 1- What do you like best about the newsletter?
- 2- What would you want more coverage on?
- 3- Where do you get most of your healthcare info?

*Everyone responding will receive a Thank you gift!*

## Did You Know...

**Asthma** kills more than 5,000 people each year, yet experts believe that almost all of these deaths are preventable by keeping the disease "under control." The problems arise because patients have inadequate access to care or don't get proper treatment. There are new guidelines for patients to better enable their management of the disease; details can be seen at: <http://www.aaaai.org/>

The recent death of **Dana Reeve** from lung cancer at the age of 44 brings into focus the need to recognize the impact that Lung Cancer has on our society and women in particular. Lung cancer kills more American men and women than colon, breast and prostate cancers combined. More critically, lung cancer is the number one cancer killer of women and it has shown a four-fold increase in women over the last 30 years. Because of these facts, it is recommended that smokers and former smokers should be screened for lung cancers in an effort to identify early stage disease, which has the best chance for cure. Information can be found at: [www.womenshealthresearch.org](http://www.womenshealthresearch.org) and [www.med.cornell.edu](http://www.med.cornell.edu)

A recent study published in the **New England Journal of Medicine** shows that Americans, regardless of race and/or socio-economic status, got roughly equal – MEDIOCRE – treatment. While the study did support evidence that minorities received worse care in some expensive treatment protocols and suffered more from some conditions than whites, data showed that once they were in treatment, minority health care overall was similar to whites. The study was based on a survey of approximately 7,000 patients. Details can be found at: <http://nejm.org> and [www.ahrq.gov/qual/nhdr05/nhdr05.htm](http://www.ahrq.gov/qual/nhdr05/nhdr05.htm)

The **number of uninsured Americans** over the age of 50 increased from 13% to nearly 15% during the period of 1994 to 2004, according to a study by the Robert Wood Johnson Foundation. 57% of uninsured adults don't have a personal doctor compared to 16% of those with insurance. 41% of uninsured adults did not see a doctor because of cost versus the 9% with insurance. West Virginia had the highest percentage of uninsured residents at 57% compared to North Dakota with the lowest at 24%.

*-Dailypress.com*

# Notes from ASCO 2006...

## Did You Know...

Researchers at Rutgers have found that the spice, **turmeric**, when combined with vegetables such as broccoli, Brussels sprouts, kale, cauliflower, turnips that contain a substance phenethyl isothiocyanate (PEITC) demonstrates significant cancer preventive qualities in lab mice. Additional studies in humans still need to be done to assess the overall efficacy and benefit in humans. Further details can be found at: [www.rutgers.edu](http://www.rutgers.edu)

Studies done at the San Francisco VA Medical Center and the University of California San Francisco have shown that **Omega-6 fatty acids**, such as in corn oil, caused human prostate tumors to grow twice as fast as tumors without the addition of Omega-6 fats. Additional information can be seen at: <http://cc.ucsf.edu/news/080105.html>

Swedish scientists have shown that foods high in content of **phytoestrogens**, plant-produced estrogens, may lower the risk of contracting prostate cancer. Researchers at the Karolinska Institutet demonstrated that a diet rich in beans, soy products, linseed, sunflower seeds, berries and peanuts lowered the risk of developing prostate cancer by 26%. Study details can be found at: [www.ki.se](http://www.ki.se)

**Vitamin D** may be effective in controlling the growth of prostate cancer in patients with two specific types of enzymes. The researchers at the University of Rochester Medical Center reported their findings in Carcinogenesis based on in vitro studies using human prostate cancer cells. Further work needs to be done based on the toxicity shown from the high doses of Vitamin D used; however, existing research shows increasing evidence that Vitamin D can inhibit the progression of the disease. Until definitive protocols are determined, the best way to get Vitamin D is to drink milk, get moderate exposure to the sun and take a vitamin supplement. Details are found at: [www.urmc.rochester.edu](http://www.urmc.rochester.edu)

The American Society of Clinical Oncology (ASCO) held their Annual Meeting in June to present data on many new therapies that addressed the full spectrum of cancer care throughout the world. It is extremely important that patients, survivors and caregivers make themselves aware of these new developments to provide a framework for discussion of their personal disease management concerns with their healthcare professionals. You can access the presentations, meeting abstracts and other relevant information from the meeting by visiting: [www.asco.org/vm](http://www.asco.org/vm). This **Virtual Meeting** site provides the most comprehensive collection of multi-media information needed.



While there were no major groundbreaking developments presented, there were several significant advances in disease management across the spectrum of sites. The following is merely a random selection of those presentations that were felt to be relevant by our editorial staff. You should review the full spectrum of presentations for discussion with your doctor.

### Cancer Education/Prevention:

There is a significant and widespread misunderstanding of prostate cancer terms and functions among men of lower socio-economic status, as reported in a study among researchers at the University of North Carolina, University of Virginia et al. The key conclusion suggests that increased emphasis be placed on health literacy and baseline understanding of prostate cancer as well as anatomical function.



Dr. Jeanna Walsh from the Wilmet Cancer Center presented an important poster on improving clinical trial participation. Given that only 3% of adult cancer patients in the U.S. participate in clinical trials, there are obvious and perceived barriers to expansion. The key conclusions and directions noted revolved around the concept of the participant as a “guinea pig” and that the participant was not assured of being given the tested drug or a placebo. Effective trial recruitment must clearly state all trial protocols, use of placebos, how Standard of Care will be included as part of the trial, and communicate in terms that can be understood by the lowest literacy level candidate. More importantly, the education must extend beyond a targeted patient population and focus on the general public’s knowledge and perceptions of clinical trials.



The effects of calcium and Vitamin D in preventing breast cancer have not yet been proven through randomized trials: though several previous observational trials have shown favorable impact. Dr. Rowan Chlebowski from UCLA presented his findings, which showed no difference in the number of cases of breast cancer between the study and control groups; yet the group taking the supplements did show smaller tumors. Dr. Carol Fabian commenting on the study suggested that, though controversial, a recommended intervention of 1,000mg – 1,200mg of calcium plus 1,000IU – 2,000IU of vitamin D or 15-20 minutes of sun exposure daily could be viable.



The Research Advocacy Network presented a poster that emphasized the benefit of preparatory lectures or training for advocates (community workers, etc.) to maximize the understanding of research data so that the details can be better communicated to their constituencies in hopes of gaining increased clinical trial participation.

### Breast Cancer:

Initial results from the Study of Tamoxifen and Raloxifene (STAR) show that equal benefit can be gained from either drug in preventing invasive breast cancer. Dr. Donald Wickerham reported on the study, which also showed that Raloxifene was just as effective as tamoxifen in preventing primary invasive breast cancer, but not as effective with non-invasive disease.



# Notes from ASCO 2006...

## Prostate Cancer:

Dr. Joel Nelson from the University of Pittsburgh presented results of a study that evaluated the effect of atrasentan (Xinlay) on PSA Doubling Time among men with hormone-naïve prostate cancer experiencing PSA rise after radical prostatectomy. The results showed that atrasentan had no effect on PSADT versus the placebo; however clearer results could not be made because the baseline PSAs were imbalanced in the participant population, which inhibited the ability to measure the true treatment effect on PSA Doubling Time.



Several studies and posters highlighted the positive impact of zoledronic acid (**Zoladex**) in reducing the risk of developing a skeletal related event (bone metastasis). Additional detail can be found in the Clinical Care Options Capsule Summaries noted below.




In a study lead by researchers at Massachusetts General Hospital, **Toremifene Citrate** was found to increase Bone Mineral Density and thereby providing a reduction in fractures in men with prostate cancer undergoing androgen deprivation therapy. These preliminary results are scheduled to be tested in an on-going study.



Key data on Prostate Cancer treatment can be seen in **Capsule Summaries** that can be viewed at: <http://clinicaloptions.com/Oncology/Conference%20Coverage/Clin%20Oncology%20June%202006/Tracks/Prostate.aspx>

## Quality of Life:

End-of-life interventions are becoming more important in the area of comprehensive cancer control as reported by the Michigan Public Health Institute and Hospice of Michigan. Hospice and pain management protocols have increased, but vary according to racial/socio-economic perceptions. While 93.5% of patients were prescribed pain medication, over 30% did not take them because of fear of addiction. Indicative of treatment practices and stage at end-of-life intervention, Blacks and Asian Americans tended to die in hospital, while Caucasians were more likely to die at home or a nursing facility and Latinos and Native Americans tended to die at home. 

# A Commitment to Advocacy....



Cancer Survivorship is a most important issue because there are more than **10,000,000 people living with cancer** today and the number is expected to increase as the “Baby Boom” generation matures, experiences a diagnosis of cancer, confronts it and then proceeds to re-claim their lives after cancer.

The American Society of Clinical Oncology (**ASCO**) has been in the forefront of making survivorship an important part of the clinical treatment protocol and in making advocacy a core element of the organization’s mission. Patient Advocates are invited to become members of ASCO with access to the same information available to healthcare professionals so that the advocates can present the information to their communities and

constituencies. Additionally, ASCO spotlights the role of advocates by offering their organizations the opportunity to exhibit at major ASCO events enabling them to convey their messages to the worldwide audience of healthcare and industry professionals.

For a review of the patient-centered information offered by ASCO, visit: [www.plwc.org](http://www.plwc.org) to see a comprehensive oncologist-approved dataset available by multiple disease sites.

Those advocates looking to take more proactive stances should explore the membership and advocate-specific programs available, which are coordinated by Jeannine Salamone (shown here). Her contact information is:

ASCO  
1900 Duke St. – Suite 200  
Alexandria, VA 2231 4  
Phone: 703.299.1014  
Email: [salamonj@asco.org](mailto:salamonj@asco.org)

## Did You Know...

**Healthgrades**, a healthcare ratings company, conducted a study that measured the rates of mortality and incidence of complications across 26 procedures and diagnoses in hospitals that ranked in the top 5% in quality of care in the Healthgrades ratings. The study found that 152,966 lives could have been saved and 21,896 instances of complications could have been avoided if the standard of care in all hospitals matched that of the top 5%. Details on the designated Distinguished Hospitals for Clinical Excellence can be seen at: [www.healthgrades.com](http://www.healthgrades.com)

Researchers at the University of Alabama at Birmingham reaffirmed the link between vision problems and erectile dysfunction drugs. Men with histories of heart trouble, who had taken either Viagra or Cialis, were 10 times as likely to have optic nerve damage as those who had not.  
- *Business Week*, February 13 2006

A new study published in the Journal of the American Medical Association showed that older Americans spend more than twice as much as people in the United Kingdom. However, the English are far healthier with lower rates for heart disease, stroke, diabetes and cancer.  
- *AARP Bulletin* / July-August 2006

The Charlotte Kimelman Cancer Institute in St. Thomas U.S. Virgin Islands opened the first state-of-the-art radiation treatment center in the Caribbean providing the ability to treat cancer patients locally without their having to travel to the U.S. The IMRT system coupled with 3-D therapy planning enables doctors to create personalized treatment plans for each patient.  
- *Caribbean Net News*

## Financial News Highlights

**Abraxis BioScience** represents a significant opportunity to invest in the biotech sector, according to David Phillips on Seeking Alpha, based on their proprietary chemotherapy delivery system that uses albumin wrapping versus the current solvents used in taxane based therapies. The result should be an increase in the amount of drug delivered to the tumor target with a reduction in the toxicities seen in the solvent wrapped taxanes. The company currently has five on-going trials in prostate cancer, six in ovarian cancer and twelve in non-small cell lung cancer. The company trades under the symbol ABBI

## Financial News Highlights

**Intuitive Surgical** (ISRG – Nasdaq) showed an 86% sales increase, a 68% gain in gross margin and net income increase of 301% on the strength of sales of their DaVinci robotic surgical systems. Despite a cost of \$1,000,000+ per system, the demand for the product for prostate surgery continues to be strong with 428 units already installed worldwide and the potential for expansion into other areas suggests further increases.

-*Motley Fool*

**Novacea** (NOVC – Nasdaq) announced that the underwriters of their initial public offering exercised their over-allotment option to purchase an additional 657,500 shares of the company. Novacea is a biotech specializing in the development of cancer therapies. One of the key products is DN-101 currently in Phase III trial for the treatment of androgen-independent prostate cancer.

- *Market Wire*

**GPC Biotech AG** had major revenue increases in the 1st Quarter 2006 while decreasing their per share net losses. The company specializes in developing new anti-cancer drugs. Their product – satraplatin – has an ongoing Phase III clinical trial as a second-line chemotherapy treatment for hormone refractory prostate cancer, which has been granted fast track status by the U.S. Food and Drug Administration. The stock trades under the symbol GPCB on the Nasdaq.

-*PRNewswire*

### American Medical Systems

**Holdings** has acquired Laserscope in an effort to expand its offerings of prostate treatments to urologists.

-*Bloomberg.com*

**Celera Genomics** reported an improvement in 2nd Quarter results and significant progress in their research portfolio of proteomics and genomics platforms. The company stated that they have validated 38 cancer targets and another 124 targets have been selected for validation studies. The targets include pancreatic, colon, breast, lung, gastric and prostate cancers. The stock trades on the NYSE under the symbol CRA.

# The Prostate Net

## 2006 "IN THE KNOW" AWARDS



## Calls For Nominations

In 2005 **The Prostate Net** honored individuals and organizations that had demonstrated leadership, implementation of novel strategies and/or commitment in time, energy and resources toward the elimination of health disparities.

Details can be seen at: [www.theknowledgenet.info](http://www.theknowledgenet.info)

### 2006 NOMINATIONS

This year on September 14, 2006 we will recognize a new group of Award Honorees at a luncheon event in New York City.

Send Your Nominations to:

**The Prostate Net,  
P.O. Box 2192**

**Secaucus, NJ 07096**

Or via Email to: [virgil@prostatenet.org](mailto:virgil@prostatenet.org)

Should you have any questions, contact us at 1.888.477.6763

## Resources

**Virgil's Prostate On-line**  
patient information site  
[www.theprostatenet.com](http://www.theprostatenet.com)

**Prostate Net Patient Hotline**  
1.888.4ProsNet (477.6763)  
24/7 live operator (in English and Spanish) intake for counselor follow-up

### Know Your Options

informational brochure on understanding the process of diagnosis and treatment - in English and Spanish



### Talking With Your Doctor

informational brochure for patients and physicians to encourage effective communication between doctor and patient to achieve best treatment protocols



# KnowledgeNet BARBERSHOPS IN HARTFORD, CT-A CAPITAL IDEA

A unique partnership between The Prostate Net, the Hartford Hospital, and the Connecticut Cancer Partnership launched the Barbershop Initiative: "Going to the Barbershop to Fight Prostate Cancer" into two neighborhood barbershops in Hartford in April. The Hartford Hospital already has a trained group of people who are key to the success of this program: barbers. "For a black man the barbershop is the country club," says Virgil Simons, the founder of The Prostate Net and a prostate



*Olphni Davis, Virgil Simons*

cancer survivor. And the barber is the director of this health education movement focusing on African American men. Barber/owners like Olphni Davis, of the Shallimar Unisex Salon, knows local barbershops are important gathering places in the community. He prefers a casual approach to a sensitive subject. He might mention that he recently had a test for prostate cancer himself or ask the man in his chair what he knows about the disease. This conversation can lead to a referral to a local doctor or to the flat-screen monitor and computer in the shop. At this educational kiosk he can get detailed information about prostate cancer, from screening to prevention. If he completes a brief survey, including items like his family medical history, the reward is a coupon for a free haircut

The barbershops participating in the Hartford area are:  
Shallimar Unisex Salon--653 Blue Hills Avenue  
Supreme Clientele--92 Weston Street

For details on the Barbershop and KnowledgeNet Initiatives, go to: [www.theknowledgenet.info](http://www.theknowledgenet.info)

## Financial News Highlights

**Alkermes** has been given an "outperform" rating by FBR Equity Research based on its partnership with Johnson & Johnson and Cephalon in marketing several drugs for antipsychotic and diabetic conditions. The stock trades on the NASDAQ under the symbol ALKS

**Novartis** reported gains in sales, operating income and market share on the strength of their product portfolios in Cardiovascular and Oncology Pharmaceuticals as well as Consumer Health and Sandoz. The company has increased the proposed dividend for 2005 by 10%. US shares of the company trade on the NYSE under the symbol NVS

**Sanofi-Aventis** lost a case in U.S. courts, along with their partner QLT of Canada, after being sued by TAP Pharmaceuticals which alleged that the drug Eligard infringed on one of the TAP patents. Sanofi-Aventis is appealing the ruling; the company's stock was down slightly on the news

Bear Stearns has maintained an "underperform" rating on **Schering-Plough** based on a Federal Court's decision not to block a generic allergy drug that competes with Schering's drug Nasonex. The analyst indicated that there was some "substitution risk" to GlaxoSmithKline's comparable drug, Flonase. Prime competition will come from Roxane Laboratories, Par Pharmaceuticals and three new companies contemplating applications: Teva Pharmaceuticals, Dey and Hi-Tech Pharnacal.

*-Reported by Forbes.com*

**Dendreon** reported a fiscal 2005 net loss of \$81.5 million vs. a net loss of \$75.2 million for the previous year. Revenue declined to \$0.21 million from \$5 million in the comparable period. Looking toward 2006, the company plans to submit an application to the FDA for the drug, **Provenge**, based on expected clinical trial results during the course of this year.

*-RTTNews*

## Did You Know...



**Dr. Mack Roach III**, chair of the Department of Radiation Oncology at University of California San Francisco, has been named one of the 10 Most Influential African-Americans in the Bay Area for 2005. Dr. Roach, a foremost cancer researcher, is a specialist in the treatment of prostate cancer and a contributor to the education efforts of The Prostate Net.

# Information on Clinical Trials

**The RENEW (Reach out to Enhance Wellness in older survivors)** study at Duke University Medical Center aims to improve the physical function of long term cancer survivors through a home-based diet and exercise intervention. The study is free and can be done completely at home. Participants will be 65 years of age or older, be survivors of colorectal, breast or prostate cancer that has not progressed and have had no second cancer diagnosis.

Details can be obtained by contacting:  
Denise Snyder  
1.877.239.1054  
RENEW@geri.duke.edu

The NCI is seeking participants for a trial of an antiangiogenic agent and a novel immunotherapeutic agent targeting CTLA-4 in the **treatment of pancreatic ductal adenocarcinoma.**

Details can be found by contacting:  
Richard E. Royal, MD, FACS

National Cancer Institute  
Clinical Research Institute  
10 Center Drive – Rm 4-5  
940 – MSC 1201  
Bethesda, MD 20892-1201  
Phone: 301.496.3098  
Email: richard\_royal@nih.gov

## Locating a Clinical Trial:

The Prostate Net  
[www.prostate-online.com/astclinic.html](http://www.prostate-online.com/astclinic.html)  
1.888.477.6763

National Cancer Institute  
1.800.4.Cancer  
[www.cancer.gov/clinical\\_trials/](http://www.cancer.gov/clinical_trials/)  
American Cancer Society  
Clinical Trials Matching Service  
<http://clinicaltrials.cancer.org>  
1.800.303.5691

The Wellness Community  
1.800.814.8927  
[www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)

[www.centerwatch.org](http://www.centerwatch.org)

The National Cancer Institute (NCI) is recruiting for a trial on a **Targeted Therapy for Metastatic Prostate Cancer**, which is a Phase II study of Docetaxel, Bevacizumab, Thalidomide and Prednisone in Patients with Metastatic Androgen-Independent Adenocarcinoma of the Prostate. Preliminary results have shown improved survival benefits.

Details can be found at:  
<http://cancer.gov/clinicaltrials/NCI-04-C-0257>  
1.888.NCI.1937

## Understanding Clinical Research

[www.prostate-online.com/research.html](http://www.prostate-online.com/research.html)



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