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Us TOO[®]
PROSTATE CANCER
EDUCATION & SUPPORT

HOTSHEET

June 2005

US TOO INTERNATIONAL ACCEPTED AS NATIONAL HEALTH COUNCIL MEMBER

The Us TOO Board and staff are pleased to announce that Us TOO has been accepted as a Member of the National Health Council in the Voluntary Health Agency category. This follows a formal application and review of Us TOO's corporate structure, financial information and operating policies.

From its inception in 1920, the National Health Council has counted among its membership most of the major health-related organizations in America.

Us TOO joins 50 other Voluntary Health Agencies including the American Cancer Society, the Alzheimer's Association, Easter Seals, the American Lung Association, the Lance Armstrong Foundation, the National Multiple Sclerosis

Society, Y-ME National Breast Cancer Organization and other leading voluntary health organizations.

There are also members of the National Health Council's Professional and Membership Organizations such as the American Dietetic Association and the MedicAlert Foundation International; Non-profit Organizations such as AARP and Community Health Charities; and Business and Industries such as the Kimberly-Clark Foundation and other pharmaceutical companies.

The National Health Council serves more than 100 million people with chronic diseases and/or disabilities and their families by providing them with information and advocating on their behalf.

Membership in the National Health Council will give Us TOO access to education and networking opportunities, publications and technical assistance as well as new partners in the advocacy arena.

VISIT THE 2005 AACR ANNUAL MEETING WEBCAST

If you missed any key sessions or were unable to attend the 96th Annual meeting of the American Association of Cancer Research, visit the Webcast, free of charge, at www.aacr.org. More than 100 scientific presentations are featured as audio and video lectures and as PowerPoint slideshows.

AACR's Annual Meeting is the oldest and largest multidisciplinary meeting in the world focused on the most timely and significant research results in all the scientific disciplines relevant to cancer. All scientists studying the causes, diagnosis, treatment, and prevention of cancer benefit from attending. Practitioners learn the latest research findings in all areas of cancer research and how to implement these findings in cancer management.



NATIONAL HEALTH COUNCIL

The Council and its member organizations share a common objective: improving the health of all people, particularly those with chronic diseases and/or disabilities.



US TOO PUBLICATIONS

In addition to the *HotSheet*, Us TOO offers a FREE e-mail based service called *NEWS You Can Use* sponsored by Sanofi-Aventis, providing updates on the latest prostate cancer related news. To subscribe or link to the archives, simply visit the Us TOO website www.ustoo.org.

Items contained in Us TOO publications are obtained from various news sources and edited for inclusion. Where available, a point-of-contact is provided.

References to persons, companies, products or services are provided for information only and are not endorsements. Readers should conduct their own research into any person, company, product or service and consult with loved ones and personal physician before deciding on any course of action.

SCIENTIFIC PEER REVIEW OF PROSTATE CANCER RESEARCH PROPOSALS FOR THE DEPARTMENT OF DEFENSE

During April, prostate cancer advocates including Us TOO International Board President Jim Kiefert and Treasurer Greg Bielawski participated in the evaluation of research proposals submitted to the Prostate Cancer Research Program (PCRP) sponsored by the Department of Defense.

As consumer reviewers, they were full voting members, along with prominent scientists, at meetings to determine how Congress' appropriation of \$85 million will be spent on future prostate cancer research. This funding program is managed by the U.S. Army Medical Research and Materiel Command (USAMRMC) Congressionally Directed Medical Research Programs (CDMRP) at Fort Detrick, Frederick, MD. Since 1997, congressional appropriations for the PCRP have totaled \$650 million.

Consumer reviewers are asked to represent the collective view of prostate cancer survivors and patients, family members, and persons at risk for the disease, when they prepare comments on the relevance of the research to issues such as disease prevention, screening, diagnosis, treatment, and quality of life after treatment.

Consumer advocates and scientists have worked together in this unique partnership to evaluate the scientific merit of prostate cancer research proposals since 1997. To date, 325 consumer reviewers have participated alongside scientists in the review process. Colonel Kenneth Bertram, MD, an oncologist and Director of the CDMRP, expressed his appreciation for the consumer advocates' perspective in the scientific review sessions.

"They have provided valuable insight into funding decisions and helped the scientists understand the consumers' perspective of innovative research. Likewise, the consumer advocates have been enriched by learning more about prostate cancer through discussing proposed research with scientists and seeing the future hopes of successful research."

BONE-PROTECTIVE ONION COMPOUND IDENTIFIED

Swiss researchers have identified a compound in onions that they believe is responsible for the inhibitory effect of the vegetable on bone resorption, and could yield new treatments for osteoporosis. The article was published in the *Journal of Agricultural and Food Chemistry* online.

Quoting earlier research, Herbert Wetli (University of Bern) and colleagues explain that the addition of 1 g of onion to the food of rats significantly inhibited their bone resorption. The purpose of the current study was to isolate and identify the bone resorption-inhibiting compound.

The team extracted onion powder and then fractionated the extract using high-performance liquid chromatography, which yielded a single active peak. Using a combination of mass spectrometry and nuclear magnetic resonance spectroscopy, they identified the active component as a peptide called gamma-L-glutamyl-*trans*-S-1-propenyl-L-cysteine sulfoxide (GPCS).

To test its effects on bone, the researchers stimulated bone loss in bone cells isolated from newborn rats using parathyroid hormone, and then treated some of the cells with GPCS. They thus found that the loss of bone minerals, such as calcium, was indeed significantly inhibited by GPCS.

Medical News Today, 4 April 2005

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ILLINOIS JOINS NATIONAL PROSTATE CANCER PROJECT FUNDED BY CDC

By Diane Johner

The Macon County Health Department hosted state wide training for the Us TOO International Prostate Cancer program on Thursday, April 28, 2005. Gene Wheeler, Program Director for the Us TOO International's Minority and Underserved Populations Prostate Cancer Awareness and Early Detection Program, served as training facilitator.

The prostate cancer program is a pilot program funded by a grant from CDC and implemented by Us TOO International and began one year ago in Mississippi, Louisiana, West Virginia and Texas; and is now expanding to include Illinois. The goal is to increase the awareness of prostate cancer in minority and underserved men (and their companions and families); thereby increasing the likelihood they will seek initial baseline PSA and DRE testing, and continue to obtain the tests on an annual basis. The project hopes to reach 25,000 people in 2005.

Individuals from Rockford, Knoxville, Springfield, and Decatur received certification to begin the national outreach program in Illinois. Deb Ellis, Bob Jelks, Diane Johner, Bob Johnson, Pattie Johnson, Mark Hunter, Georgia McKinney, Robert Moore, Jenna Murray, LuAnn Ostrander, David Rogers, Kathy Walker, and Diana Weyhenmeyer successfully met all the requirements and fulfilled all the obligations necessary to be certified as a Prostate Cancer Community Awareness Educator. Ms. Johner, Director of Health Promotion at the Macon County Health Department and member of the advisory panel for the International



ILLINOIS PROSTATE CANCER COMMUNITY AWARENESS COUNSELORS

Us TOO Prostate Cancer Program states "The purpose of the program is two fold-inform men and women of the risk associated with prostate cancer and encourage men to take responsibility for their own health."

Illinois plans to implement the project at various community health fairs throughout the state and at the Farm Progress Show on August 30, 31 and September 1, 2005 in Decatur, Illinois.



David Rogers receives his certificate as an Illinois Prostate Cancer Community Awareness Educator

GREEN TEA MAY CURB PROSTATE CANCER IN MEN AT RISK

Compounds found in green tea may prevent the development of prostate cancer in men with a pre-cancerous condition called high-grade intraepithelial neoplasia (PIN), researchers have shown.

"The sad truth is that close to 30,000 men will die from prostate cancer in the United States every year and, at present, prevention is the best way to fight it, Dr. Saverio Bettuzzi from the University of Parma in Italy told Reuters Health.

High-grade PIN progresses to invasive prostate cancer within a year in about 30 percent of men and no treatment is given to these men with high-grade PIN until prostate cancer is diagnosed.

Green tea catechins (GTCs) may be the answer, Bettuzzi said at the gathering of the American Association for Cancer Research in Anaheim, CA.

The investigator performed a trial involving men with high-grade PIN, who were given an inactive placebo preparation or one containing 600 milligrams of GTCs daily, "equivalent to 12-15 cups of

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THE LOVING PIE, PART II

THE TOPPINGS: THERAPIES AND MEDICATIONS FOR RENEWING INTIMACY AFTER PROSTATE CANCER TREATMENT

By Barbara and Ralph Alterowitz

[Editor's Note: This is the second of two articles on reviving intimacy after prostate cancer treatment. The first article appeared in the May 2005 Us TOO *HotSheet* and dealt with laying the basis for good loving. This article talks about the many therapies available for treating erectile dysfunction, how to use them, and their side effects].

To briefly review the loving-pie metaphor, the crust is the quality of the relationship and how the partners interact with each other, and the filling ingredients are primarily communication, an agreement to get to know each other all over again, and an atmosphere of love. The toppings are things that can enhance the sexual experience, but are not essential for good loving.

In the context of The Loving Pie, we frame the idea of using therapies and medications as toppings. Toppings would be things a man can do or take such as one of the pills that might help him attain or maintain an erection for a specific love-making event.

Before dealing with available therapies to help men get or improve an erection, we need to talk about the degrees and causes of erectile dysfunction. Many men are not totally impotent but they may not be able to get an erection sufficient for penetration. Researchers grade the degree of penile rigidity on a scale of 1-10. In that light, a man who cannot get the same level of rigidity he remembers from his younger years would have some erectile dysfunction, but he would not be called impotent.

This brings up the first thing we need to be clear on. Aging is probably the major cause of erectile dysfunction. As the years go by, hardening of the arteries and changes in the nervous system prevent men from getting the erections they once knew. Other things also affect and change a man's ability to get an erection.

Lifestyle choices have a profound effect on overall health including erectile capability. These include diet, activity level, and factors such as smoking, drinking and use of certain prescription, over-the-counter, or even street drugs. All of these affect the body's capability to get aroused and to pump blood into the penis, allowing for a sustained erection. Fat in the diet clogs arteries in the penis as well as those that lead to the heart (and indeed in the entire body).

In addition, surgery, radiation, injuries, and physical or mental illness may cause problems with the blood circulation and may damage nerves. Erectile function is also influenced by transient emotions such as feelings of guilt or anxiety about having an erection. Impaired blood circulation and/or nerve damage causes a man to need more time to get an erection and often more direct stimulation.

For prostate cancer patients, treatment may also cause or worsen erectile dysfunction:

1. After surgery, even with nerve-sparing techniques, a man's remaining erectile ability may take two years or even longer to recover. Nerves are damaged or at least manhandled during surgery, so even if potency returns, it is often less than before.
2. Radiation of all types will reduce a man's erectile capability, but at a slower pace than surgery. However, after four years, the percentage of men with erectile difficulties is the same for both surgery and radiation.

Penile Rehabilitation

An important therapy to aid in recovering erectile capability that all men should consider in consultation with their health care professional is what is now called penile rehabilitation therapy. To put it simply, this therapy is based on using medication or a device almost daily to produce erections, *not* for the purpose of intercourse but rather to get blood flowing into the penis. Vacuum pumps, injections, or pills may be all prescribed for this purpose. As is obvious, some means are less expensive than others.

For the newly diagnosed prostate cancer patient, it is important to be aware that a nerve-sparing procedure is not always an option. The patient may want to explore with his doctor whether neural grafting might be feasible in such a case. This procedure involves taking a nerve from the ankle or the lower part of the abdomen and filling in the neural gap near the prostate gland, where nerves have been cut. This must be done at the same time as the prostatectomy.

THE TOPPINGS

Ideally, it would be nice to have one therapy that everyone can use to achieve an erection. We would all like a single therapy that:

- is effective,
- works when it's needed,
- is not toxic and has no side effects,
- is easy to use such as pills or cream, and
- is inexpensive.

Given that such a wonderful all-purpose medication does not exist, let's look at the therapies and medications that are available. These are just highlights and do not provide the comprehensive medical information a man needs to make an informed judgment. Any approach a man wants to use should be discussed with his doctor or other health care professional.

In the past five years many commercial therapies—medications and aids—have become available to swell the arsenal of options to help men get an erection. The list consists of:

- oral medications
- injectible medications
- transurethral drug therapy
- a broad range of devices that include vacuum erection devices (VED), constriction rings, penile splints, and even vibrators. These are external devices for aiding a man in obtaining an erection at the time it is needed.
- Penile implants are internal devices that are surgically implanted for long term use.

Before using any aid, there are a number of things to think about:

- Try a medication or aid only if both partners want to. You need to know how each of you feels about using them.
- Each aid has its own advantages, drawbacks, and side effects.
- Medications may not work equally well all the time. A product that works one time may not work as well, or at all, the next time or later on. And one that has not worked one time may work another time. Some work better with longer-term use. None are guaranteed to work, and many work only on a certain percentage of patients.
- Many of the drugs have considerable side effects.
- The drugs and devices aid in obtaining erections, not orgasms. On the other hand, a man can have an orgasm without an erection.

Conservative medical guidance is to start with a low dosage and work your way up as necessary. Follow your physician's advice concerning drugs and dosages. Sometimes a physician may start a patient with a high dosage to increase the probability that the patient can experience some success.

Oral medications

A pill fits the primary feature that a man generally looks for in erection medication: it should work quickly. A man is likely to think in terms of a popular ad for one pill – “will you be ready?” When he needs it, he wants it to work almost immediately without any fuss or bother.

Three pills are currently available: Cialis®, Levitra®, and Viagra®. There are differences between the three that refer to how quickly they act, how they should be used, dietary restrictions and side effects.

It is mandatory that the man be aroused before any of the pills will work. Levitra and Cialis promotions say that a man can achieve an erection about 20 minutes after being taken. Soon after their announcements, Pfizer announced that Viagra, the first pill available, can also work in about 20 minutes to a half-hour. Previously, Pfizer's instructed users to observe the dietary restrictions, i.e., it should be taken two hours after an, ideally, low fat meal. Then the man must wait 20 minutes to an hour before he would have the capability to have an erection if he is aroused. Levitra and Cialis, do not have the same dietary and time restrictions.

A cautionary note is that all medications must be taken under medical guidance. A physician must determine the appropriate dose consistent with the patient's medical history. Unfortunately, although these are prescription products, many knockoffs are offered over the internet. While the prices may seem attractive, the quality of production, the content of the pills cannot be verified, and the consequences of taking these pills are unknown. Moreover, using these pills without medical supervision puts patients at great risk.

Another point worth noting concerns using pill cutters to obtain more than one dose from a pill. It may seem

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THE LOVING PIE, PART II

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logical to split a large-dose pill in half. The drawback is that the active ingredient may not be evenly distributed throughout the pill, so the dosage in each part is different. Also, breaking the coating may alter the effectiveness or produce side effects if the drug was designed to be absorbed in a certain place in the digestive system.

Men should be aware that these drugs do not increase desire. All they do is help a man who already is aroused achieve an erection – if they work for that man. And for many men, they may not work at all.

Injections

Injections essentially always work and yield quick results, but it means taking time for an injection into the penis. The most well-known, Caverject®, also has several competitors, Edex® and Invicorp®. Many men feel queasy inserting a needle into their penis. The actual effect is a slight pin prick. The quick insertion in the correct position provides a prompt erection. Many men preferred the injection even after Viagra became available because of the latter's food and time restrictions. One group of injection medications, called blends, has the advantage that a doctor can tailor them according to a patient's needs and to minimize side effects.

Intraurethral Medication

MUSE requires that a man insert a very thin syringe into the penis to deposit a tiny pellet or suppository deep into the urethra. As with many medications, the man's responsiveness in terms of erectile capability varies. The manufacturer, Vivus, introduced a ring, a clamp-type device, Actis®, that men can use to retain the erection. This ring is similar to the constriction rings available with vacuum erection devices.

Devices

The best known of the external devices are vacuum erection devices, known interchangeably as VEDs or pumps. These are mechanical appliances to aid men in obtaining an erection. The upsides are the ability to obtain an erection fairly easily, reliably, and without medication side effects. However, some men and partners are turned off by the need to stop and use the pump. Some manufacturers suggest that both partners participate in using the device so that its use becomes part of lovemaking.

For most men, using the pump will also require the use of a constriction ring to keep the blood in the penis and thereby retain the erection.

VEDs are also often prescribed by physicians as the preferred means for penile rehabilitation mentioned previously. Although there may be a higher initial cost than injections or oral medication, over a long period, it may cost less.

A penile splint may be used for rigidity to enable penetration. However, it must be used with care.

Penile implants are for men desiring long term solutions for obtaining erections almost at will. They must be implanted surgically. Some implant procedures are performed as outpatient surgery, and all surgery carries risks such as post-operative infection, pain, and device malfunction. These risks have been reduced in recent years. Current devices are quite reliable and can last anywhere from eight to twenty years. Patients report high levels of satisfaction.

THERAPIES IN COMBINATION AND DEVELOPMENT

Even with all the recent advances, the current therapies are not ideal and do not work for some men. Some therapies may be used in combination such as a clinician prescribing a pill to be used with a vacuum device. This increases the success rate for some men, but must only be done in consultation with a physician.

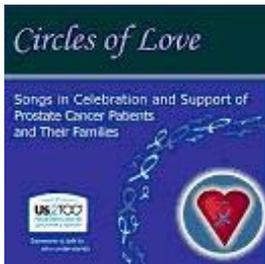
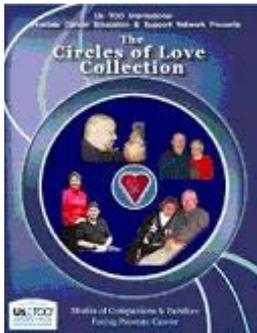
Clinical studies are in progress exploring the value of other approaches. A topical, gel-type product is still being studied in the U.S. but is already in use in Asia. New oral therapies are in clinical studies that may work on the nervous system and on muscles. Pfizer's early breakthrough with Viagra, and the demand for all pills, seems to have spurred companies to unlock the research gates to help men improve their erectile quality.

There are many "toppings," or means, to aid men in obtaining an erection. But the underlying satisfaction in sexual intimacy must be the relationship between the partners and the erection is for a little extra spice.

Think Love! Make Love!

Ralph and Barbara Alterowitz, husband and wife, are popular speakers, intimacy counselors and co-authors of Intimacy with Impotence: The Couple's Guide to Better Sex After Prostate Disease, (2004, Da Capo Press). The book is available through www.renewintimacy.org with proceeds furthering education efforts on intimacy after cancer, at bookstores, and is part of Us TOO's Circles of Love Care Kit, and education and support program for companions and family members of prostate cancer patients. Us TOO Circles of Love Care Kits are available at www.ustoo.org or 1-800-808-7866. Barbara and Ralph are prostate cancer activists and members of the American Association of Sex Educators, Counselors, and Therapists. They can be reached at info@renewintimacy.org.

US TOO FEATURED RESOURCES

To order or find, visit www.ustoo.org

- 1) **NEW! *The Circles of Love Care Kit*** – \$24.99 includes S+H

Our new care kit is an excellent resource collection for friends and loved ones of those facing the battle against prostate cancer. Our care kit includes:

- ***The Circles of Love Collection: Stories of Companions and Families Facing Prostate Cancer*** This new book, an Us TOO original publication, is a compilation of interviews with friends and loved ones of prostate cancer patients. These supportive and inspirational stories are meant to help others who are facing similar challenges. Also available separately for \$17.00 includes S+H
- ***Circles of Love Music CD*** – This original collection of upbeat and inspirational songs was written to celebrate the love and support between the patient and his companions and family members. Contributing artists include Soozie Tyrell of the E Street Band, Alan Glass (who has written hits for Kenny G and others), Jerry Peters (who has written for Luther Vandross and others), country artist Deborah Allen, and folk artist Kat Eggleston. 12 songs including pop, R&B, soul, country, folk and dance. Also available separately for \$15.00 includes S+H.
- ***Intimacy with Impotence: The couples guide to better sex after prostate disease*** – This book, authored by Ralph and Barbara Alterowitz, is written for couples who have survived prostate cancer and whose normal sexual function has been disrupted. The authors bring a unique and personal perspective to the topics as they too live this experience. 220 pages.
- ***What You Need to Know about Prostate Cancer*** – from NIH and NCI
- ***“Life after Cancer Treatment” Resource and Referral Guide*** – excerpt from NCI

- 2) **NEW! Prostate Cancer Car Magnets “Know Your PSA”** – \$5.00 each plus S+H



- 3) **STRIVE Initiative Wristbands** – \$1.00 each plus S+H

- 4) **HotSheet Subscriptions** – \$35 for 12 issues

HotSheets are distributed FREE at all Us TOO Support Group Chapter meetings, and on www.ustoo.org. But what if you are unable to regularly attend chapter meetings, or don't have access to the Internet? Don't miss an issue—we can deliver it right to your home or office!

- 5) **“What You Need To Know For Better Bone Health”** – FREE Us TOO brochure

- 6) **100 Questions & Answers About Prostate Cancer** – \$14.95 includes S+H
By Pamela Ellsworth, MD, John Heaney, MD, Cliff Gill

- 7) **Prostate Cancer Resource Kit** – \$18.95 includes S+H

Included in this handy boxed kit:

- **A Primer on Prostate Cancer** - by Dr. Stephen Strum and Donna Pogliano
- **Know Your Options** – from Us TOO and the National Cancer Institute (NCI)
- **Prostate Cancer Treatment Guidelines for Patients** – from National Comprehensive Cancer Network (NCCN) and the American Cancer Society
- **What You Should Know About Prostate Cancer** - from Prostate Cancer Research Institute (PCRI)
- **Prostate Cancer Resource Guide** - from the American Foundation for Urologic Disease (AFUD)
- **Us TOO / Phoenix 5 CD-ROM** - developed by Robert Young

- 8) **Understanding Prostate Cancer: A Patient's Resource Kit** – \$7.50 includes S+H

Included in this handy boxed kit:

- **Humanizing Prostate Cancer: A Physician-Patient Perspective** by Roger E. Schultz, MD (Physician), and Alex W. Oliver (Patient)
- **Living With Prostate Cancer** – booklet
- **Know Your Options** – from Us TOO and the National Cancer Institute (NCI)
- **Living With Advanced Prostate Cancer video** - patient testimonials on Viadur

- 9) **Prostate Pointers Virtual Support Communities** – FREE at www.prostatepointers.org.

- 10) **Us TOO Prostate Cancer NEWS You Can Use** – FREE e-News

Proceeds from all items benefit Us TOO's FREE programs, support services and educational materials for prostate cancer patients and their families

GREEN TEA

(Continued from page 3)

green tea infusion, that is about two times the average intake in Asian countries."

Bettuzzi reported that, after a year, only 1 man among 32 (3%) in the GTC group developed prostate cancer. In contrast, 9 out of 30 men (30%) treated with placebo developed prostate cancer, which is the rate expected.

"To our knowledge, this is the first study showing that GTCs have potent in vivo chemoprevention activity for human prostate cancer," Bettuzzi noted.

"The interest in GTCs and other polyphenols -- antioxidants found in many plants -- derives from traditional Chinese medicine, but the Mediterranean diet is very rich in vegetables, thus providing high levels of polyphenols, and lower rates of prostate cancer are found in that region as well," he pointed out.

In the near future, we are supposed to start a collaborative trial involving both Italy and USA on this matter," Bettuzzi concluded.

Reuters Health, 19 April 2005

GENETIC PROTECTION FROM MALARIA MAY FUEL PROSTATE CANCER IN AFRICAN-AMERICANS

A genetic mutation present in the majority of African Americans that protects against malaria may contribute to the increased incidence of prostate cancer, as well as the higher death rate from the disease in this population. That's according to research conducted in mice, presented at the American Society of Investigative Pathology sessions of Experimental Biology 2005 by Dr. Alex B. Lentsch, a researcher at the University of Cincinnati College of Medicine.

"In malaria-endemic areas such as West Africa, it was found that most of the population had a genetic mutation in the Duffy antigen/receptor for chemokines, or DARC receptor, that prevented the expression of the DARC receptor on red blood cells -- kind of a genetic protective mechanism against malarial infection," Dr. Lentsch explained.

There is also evidence that this same receptor binds to and removes some angiogenic chemokines from tumors, thwarting their ability to develop new blood vessels, he added.

Using mice genetically engineered to spontaneously develop prostate cancer, Dr. Lentsch and colleagues compared the growth and size of prostate tumors in animals with or without DARC.

Mice with or without DARC developed tumors at roughly the same time, which is not surprising, Dr. Lentsch said, since chemokines have not been linked to the formation of tumors. However, once the tumors were present, they grew significantly faster in the mice without DARC. "Excised tumors from mice lacking DARC compared to wild-type mice were dramatically bigger in volume and mass," he said.

"These data clearly suggest a role for DARC in more aggressive prostate cancer tumor growth in African-Americans, primarily because they do not have the receptor," Dr. Lentsch said. "This suggests that a simple blood test for the presence or absence of DARC on red blood cells could give us some information as to whether they are more likely to have aggressive tumor growth," he added.

The study was funded by the United States Army Medical and Material Command.

Reuters Health, 4 April 2005

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