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BCAN was formed in 2005 as a 501 (c) (3) non-profit organization and is the first national patient-based advocacy organization for bladder cancer. For additional information about BCAN and bladder cancer or to make a donation, please visit our website at [www.bcan.org](http://www.bcan.org).

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#### President's Message



Dear Friends,

It's hard to believe that BCAN is nearing its first anniversary, as our "birthday" is May 18, 2005. It is particularly appropriate that this event coincides with Spring, a time of growth and development.

We are thrilled to have Tate Donovan join BCAN both as a national spokesperson and a member of our Board of Directors. Tate and his family have been profoundly affected by bladder cancer. His father, Dr. Timothy Donovan, at the time a retired urologist, died of bladder cancer in 2000. His mother also was diagnosed with superficial bladder cancer in October 2005. Most recently known for his portrayal of the character Jimmy Cooper on the hit television drama "The O.C.," Tate has appeared in more than 20 movies, including "Good Night and Good Luck" and several theatre productions on and off Broadway. As a spokesperson for BCAN, Tate will appear in educational materials, as well as tell his family's story to the public to help spread awareness about the disease and its symptoms.

Tate will be joining us in Atlanta for the Annual Meeting of the American Urological Association (AUA), May 20-25. BCAN will be hosting a booth, staffed by BCAN supporters and volunteers. In addition, we will be holding a joint press conference with the AUA Foundation to announce our partnership to educate patients about bladder cancer.

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BCAN, in conjunction with Medical Education Collaborative and Dane Garvin Ltd, is co-sponsoring a Satellite Symposium prior to the AUA Annual Meeting in Atlanta. This symposium is for the urological medical community and is entitled "Bladder Cancer: Practical Considerations in the Use of Markers, A Case-Based Symposium." The program was made possible by an educational grant from Abbott Molecular, and will be held on May 19, 2006 from 3:30p.m.-5:00 p.m. at the Georgia World Congress Center.

BCAN will also be participating at the Annual Meeting of the American Society of Clinical Oncologists in Atlanta on June 3-5, as part of the Patient Advocacy Booth.

**Save the Dates:** We hope many of you will be able to join us on Sunday, June 25 as we celebrate BCAN's first anniversary with Bob Schieffer, anchor of the CBS Evening News and host of "Face the Nation." Bob is a bladder cancer survivor and a great friend and supporter of BCAN. This fundraiser (BCAN's first) will be held at the home of Toni and Dwight Bush in Washington, D.C. Watch our website for further details.

On Saturday, September 9, 2006, BCAN and the AUA Foundation are hosting the first "Bladder Cancer Patient Symposium: Update for Bladder Cancer Survivors and Their Families." The event will be held in Linthicum, Maryland (near Baltimore-Washington airport) from 9:00 a.m. to 1:30 p.m. and admission is free. Please check our website for more details as the date approaches.

We greatly appreciate the support of our growing network of volunteers across the country, whose efforts to help us raise awareness about bladder cancer are invaluable. We also want to express our sincere gratitude to all of those who have supported us during our first year. We look forward to BCAN's continued development and success.

*Diane Zipursky Quale*

On Trial



We thank Elizabeth (Betty) M. Smith, BS, CCRC, urology clinical trials manager, for providing this information on bladder cancer studies that are currently enrolling subjects at the University of Rochester. For more information on these studies, please contact [betty\\_smith@urmc.rochester.edu](mailto:betty_smith@urmc.rochester.edu).

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### **Detection of Bladder Cancer by Microsatellite Analysis (MSA) of Urinary Sediment.**

This study is to validate a biomarker to detect bladder cancer by examining genetic changes in DNA obtained through urine samples and a blood sample, a non-invasive method of screening for bladder cancer. In this study scientists will compare genes found in the subject's blood to the genes found in the subject's urine to detect different patterns or occurrence. The sponsor and Principal Site are Johns Hopkins University and Health and Human Services, NIH. The University of Rochester Site Principal Investigator is Edward Messing, MD.

### **Isoflavone (Genistein) in Subjects with Bladder Cancer.**

This study's objective is to determine the effect of Genistein on the expression of specific tumor markers for bladder cancer, to determine the effects of Genistein on enzymes and receptors expressed more generally on cancer cells, to document any genetic susceptibility to the effects of Genistein and to determine the safety and tolerance of this preparation. Effects will be measured in the urine, blood and in tumor tissue retrieved from bladder cancer surgery. The isoflavone, Genistein, a natural soy product, has documented anticarcinogenic activities. Genistein is administered orally for 14-30 days prior to bladder surgery. The sponsor is NCI, Division of Cancer Prevention, University of Wisconsin Chemoprevention Consortium, and the Principal Investigator at the University of Rochester is Edward Messing, MD.

**Hexvix Fluorescence Cystoscopy and White Light Cystoscopy in the Detection of Bladder Cancer.** The aim of the study is to see if this new investigational study drug, hexyl aminolevulinatate (Hexvix), helps study doctors to improve the detection of bladder cancer. Hexvix by itself is inactive (does not have an effect) and is changed to other substances (porphyrins) in the body which "glow" red under blue light. The production of porphyrins is much higher in cancer cells compared to normal cells and will therefore "glow" much stronger. The Hexvix is instilled into the bladder and retained for one hour prior to cystoscopy. The Sponsor for this study is PhotoCure ASA. The Principal Investigator at the University of Rochester is Edward Messing, MD.

### **Ask the Doctor**



This quarter we thank Dr. Seth Lerner, Associate Professor of Urology, Beth and David Swaim Chair in Urological Oncology and Scott Department of Urology, Baylor College of Medicine in Houston, Texas, for providing answers to the questions we

posed to him.

**Q. Can bladder cancer survivors ever count themselves in the "cured" column?**

**A.** As with most cancers, the longer one goes without a recurrence the better. The majority of patients with bladder cancer are initially diagnosed with a non-muscle invasive cancer that can be managed initially with tumor resection via cystoscopy with or without intravesical therapy. These patients however, are at high risk for developing another tumor. The majority of recurrences occur within the first two years. The status of the bladder at the first three-month follow-up cystoscopy is a very important contributing factor to remaining disease free. Recurrent tumors do occur after the critical two year period, though less frequently, and patients should continue to be followed at least annually.

For patients with invasive cancer that requires bladder removal or radiation therapy with or without systemic chemotherapy, the majority of recurrences occur within the first two to three years after treatment. This timeline may be pushed back in patients who received chemotherapy. Five years is a good benchmark for determining outcome and the majority of patients who survive five years without a recurrence are likely cured. While much less frequent, recurrences do occur past five years in patients who have remained disease free, and annual follow-up is important for this reason.

**Q. What are typical side effects of BCG? How do you know when your side effects are abnormal?**

**A.** Side effects are very common and occur in up to 85% of patients. The most common are frequent urination, painful urination and a feeling of having to get to the bathroom quickly (urgency). Blood in the urine (hematuria) is common but usually self-limited. When symptoms interfere with a patient's ability to receive treatment on schedule, a dose reduction strategy can be used which will allow most patients to continue with BCG treatment. Anticholinergic agents may also help patients with urgency and frequency. When symptoms last more than 48 hours, treatment with the anti-tuberculosis drug isoniazid may be considered. More severe side effects occur in 3% of patients or less and include fever, joint pain and swelling, severe hematuria and in men, prostatitis or epididymitis. Treatment may be continued using a dose reduction strategy and with consideration of pre-treatment with isoniazid. Systemic infection with BCG or other bacteria while rare, can be life threatening and requires treatment with broad spectrum antibiotics and

isoniazid and rifampin.

**Q. Doctors in Boston recently announced that they had successfully used cells from a patient suffering from bladder disease to grow a new bladder in a petri dish and then implanted that bladder into the patient. What implications does this development have for bladder cancer patients who need to have their bladders removed?**

A. Tissue engineering offers the hope of “off the shelf” biomaterials that can be fashioned into replacement parts, many times using the patients’ own cells to constitute a functional organ. In the report from Boston, the doctors have taken a major step forward in bladder replacement for non-cancer conditions. The patients who were treated had a congenital or acquired malfunction that resulted in a very small capacity bladder. Therefore, the described procedure was ‘bladder augmentation’ where a patch is added to increase the volume of the bladder. In achieving this remarkable feat, they used the patient’s own bladder cells to line the matrix that was then implanted on top of the existing bladder.

Since the bladder cells of a bladder cancer patient have a propensity to form tumors, an alternative source of cells is mandatory. Therefore, this model is not suitable for cancer patients. Adult (non-embryonic) stem cells can be obtained from peripheral blood, bone marrow, fat and from several other organs, virtually at any age. They offer the hope of a natural source of pre-cursor cells that can differentiate in an organ-specific fashion. Although the researchers from Boston performed a bladder augmentation and not a complete bladder replacement, the initial results are an important milestone on the way to complete bladder replacement. However, since replacing a whole bladder is more complex than the described procedure, it will probably take several more years to achieve complete bladder replacement. The field of tissue engineering is growing rapidly and there are a myriad of potential applications for reconstruction in the genitourinary tract.

### Volunteer Corner



Rosemarie “Rosie” Quigley Ambs, of Ruther Glen, Virginia, has joined BCAN as a volunteer, helping us increase awareness and distribute information about BCAN and bladder cancer in her community. Rosie has superficial low grade recurrent papillary bladder cancer. We thank her for sharing her story.

Over the past six years of treatments, tests, surveillance,

cystoscopies, four TURBs (surgery performed with a special instrument inserted through the urethra to remove a bladder tumor) and four recurrences, I have learned there is a distinct difference between my low grade recurrent papillary bladder cancer and other types and grades of bladder cancer. I have also learned of an emerging protocol change from immediate surgical removal of recurrent papillary growths to watchful waiting.

Wendy Sheridan of the Bladder Cancer Web Café told me of a presentation made by Dr. Mark Soloway of the University of Miami in 2004 in which he talked of an in- depth long term study of patients with recurrent low grade papillary cancer. After reading the study and noting the similarities in my case history, its results and subsequent recommendations, a new courage and understanding emerged in me. So, at this point I have taken the position of watchful waiting. When a new superficial papillary tumor has been detected through cystoscopy, rather than having an immediate TURB and dealing with all the risks and costs involved in the tests, pre-op, anesthesia, surgery itself and post operation, my doctors and I have decided to wait, employing careful follow up.

Being fortified with the knowledge of Dr. Soloway's study and other European urological reports and recommendations on recurrent low grade papillary cancer, when a new tumor was detected in 2004, I waited a year before having the tumor removed. The pathology report came back papillary TA grade I of III (lowest stage and grade of bladder tumor). I am now doing watchful waiting on a two millimeter re-growth seen during my February 2006 cystoscopy. I believe it to be a residual tumor from the prior TURB done last July as the newest protocol of instilling a single treatment of Mitomycin C immediately after TURB was not done. My urologist has now recommended that be done when I have my next TURB.

You can read more about my frustrating earlier experiences with blood in my urine and the early years of my bladder cancer adventure at [www.blcwebcafe.org](http://www.blcwebcafe.org) under Tales from the Trenches - superficial bladder cancer - transitional cell carcinoma and click **Rosie**.

It's Complementary



Meditation is a mind-body practice in complementary and alternative medicine (CAM) that uses concentration or reflection to relax the body and calm the mind. It has been defined as the intentional self-regulation of attention, a mental

focus on a particular aspect of one's inner or outer experience. Many people, including cancer survivors, use meditation for health purposes to increase physical relaxation, mental calmness and psychological balance; to cope with one or more diseases and conditions or for overall wellness. Most types of meditation have four elements in common: a quiet location; a specific, comfortable posture; a focus of attention and an open attitude.

Practicing meditation has been shown to induce some changes in the body, such as changes in the body's "fight or flight" response. The system responsible for this response is the autonomic nervous system. It automatically regulates many organs and muscles, including functions such as heartbeat, sweating, breathing and digestion.

The autonomic nervous system is divided into two parts:

- (a)The sympathetic nervous system helps mobilize the body for action. When a person is under stress, it produces the "fight or flight" response: the heart rate and breathing rate go up; blood vessels narrow and muscles tighten.
- (b)The parasympathetic nervous system creates a "rest and digest" response. This system's responses oppose those of the sympathetic nervous system. For example, it causes the heart rate and breathing rate to slow down, blood vessels to dilate and activity to increase in many parts of the digestive tract.

While scientists are studying whether meditation may afford meaningful healthy benefits, they are also looking at how it may do so. However, it is believed that one way some types of meditation might work is by reducing activity in the sympathetic nervous system and increasing activity in the parasympathetic nervous system.

If you are interested in using meditation as CAM, consider the following: Meditation should never delay the time it takes you to see your healthcare provider about a medical problem. It should not be used as the only treatment without first consulting your doctor. It is important to discuss any CAM therapies you are considering or using with your healthcare provider. For more information, visit the web site of the National Center for Complementary and Alternative Medicine at [www.nccam.nih.gov](http://www.nccam.nih.gov).

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