



4813 St. Elmo Avenue
Bethesda, Maryland 20814
301-215-9099 Phone
973-215-9092 Fax
info@bcan.org

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.

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President's Message



Dear Friends,

I am thrilled to report that the first educational program for the bladder cancer community, co-sponsored by BCAN and the American Urological Association Foundation on September 9, 2006 was a tremendous success.

More than 90 survivors, caregivers and family members attended this free forum which was held at the AUA headquarters near the Baltimore-Washington Airport. The program, "Living with Bladder Cancer: Treating, Understanding, Coping" included presentations by medical professionals on "Biomarkers in Bladder Cancer", "What You Should Know about Invasive Bladder Cancer", "New Treatment Horizons in Bladder Cancer", and "Coping Strategies." The audience took advantage of the question and answer sessions, and also had an opportunity to network with other bladder cancer survivors. The feedback from the participants was extremely positive. BCAN and the AUA Foundation are already planning our next patient forum for March 17, 2007 in the South Florida region.

BCAN gratefully acknowledges the support of Bristol Myers Squibb, who provided us with an unrestricted educational grant for our public awareness and education activities, including BCAN's participation in these important forums.

My husband John and I were fortunate to be invited to attend

Michael Droller, M.D.
Mount Sinai Medical Center

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Massachusetts General Hospital

Eila Skinner, M.D.
University of Southern California,
Norris Comprehensive Cancer Center

Mark Soloway, M.D., FACS
University of Miami School of Medicine

Walter Stadler, M.D., FACP

“Outside the Box #1: Bladder Cancer Think Tank” hosted by Dr. Mark Schoenberg of Johns Hopkins in August in Aspen, Colorado. This gathering brought together more than 30 prominent clinicians and researchers, as well as survivors from around the United States and Canada, to discuss significant issues in bladder cancer detection, diagnosis and treatment. It was a very interesting and productive meeting, with the attendees recognizing the need to work together to increase research funding for bladder cancer and improve enrollment in clinical trials. The participants were universally enthusiastic about making this gathering an annual event, and BCAN has been asked to be the sponsor of the 2007 Bladder Cancer Think Tank. We will be working with members of the bladder cancer community to help secure funding.

BCAN's National Volunteer Board held its first meeting in September (*see Volunteer Corner*) and I'm very excited about getting this nationwide volunteer effort underway. The Board's first project is to generate some stories in local newspapers concerning the need to improve awareness and education about bladder cancer. We will be focusing our efforts on “National Bladder Health Awareness Week”, November 12-18.

Our website, www.bcan.org, now offers a Treatment Options Tool to help bladder cancer patients (especially the newly-diagnosed) understand treatment options and possible side effects, and provides the patient with questions to ask his or her doctor. This NexProfiler Tool, which is free and easy to use, is made available through NexCura, a Thomson Business.

Over the past several months, I have met dozens of people recently diagnosed with bladder cancer, lost a friend to bladder cancer, and struggled with my husband's bladder cancer recurrence and resulting surgery for removal of his bladder and prostate. All of this strongly confirms the importance of BCAN's mission not only to improve public awareness of bladder cancer, but also to increase funding for research directed at finding better treatments and ultimately, a cure for this disease.

Diane Zipursky Quale

On Trial



According to Bernard H. Bochner, MD., Assistant Attending Surgeon in the Department of Urology and Nicholas Karanikolas, MD, Urologic Oncology Fellow, there are currently five active clinical trials underway at Memorial Sloan

University of Chicago

John P. Stein, M.D., FACS
University of Southern California,
Norris Comprehensive Cancer Center

Gary D. Steinberg, M.D., FACS
University of Chicago

Dan Theodorescu, M.D., PhD
University of Virginia Health System

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Kettering Cancer Center.

I. Evaluation of Magnetic Resonance Imaging and Positron Emission Tomography for Bladder Cancer Diagnosis and Staging

This is a pilot study to explore the use of ^{11}C acetate- positron emission tomography (PET), and magnetic resonance imaging (MRI) to clinically stage patients with localized or regionally metastatic bladder cancer. Data from this study will determine necessary technical and logistical modifications in both imaging techniques and pathologic processing that would be necessary to design future definitive trials to assess the role of these imaging modalities in the management and staging of primary and regionally metastatic bladder cancer. Additionally, the biodistribution and dosimetry of ^{11}C acetate will be evaluated to determine whether it is a more suitable agent for imaging bladder cancer than the traditionally employed fluorodeoxyglucose (^{18}F FDG) compound.

Sponsor – Memorial Sloan Kettering Cancer Center
Principal Investigator – Bernard Bochner, MD

II. Genetic Susceptibility to Tumor Recurrence and Progression in Patients with Non-Muscle Invasive Bladder Cancer

This is a study of patients with non-muscle invasive bladder cancer to determine the prevalence of genetic variants in the DNA repair genes, cell cycle genes, and detoxifying genes and evaluate their association with recurrence and progression of superficial bladder cancer. Genetic variants using Single Nucleotide Polymorphisms (SNP's) will be compared to DNA damage/repair capacity as determined by the Comet Assay. Additionally, this study will explore the utility of lymphocytes as a surrogate for the DNA repair capacity of normal urothelial tissue.

Sponsor – National Cancer Institute and Memorial Sloan Kettering Cancer Center
Principal Investigators – S. Machele Donat, MD and Harry Herr, MD

III. Detection of Bladder Cancer by Microsatellite Analysis (MSA) of Urinary Sediment: Multi-Institutional Study

This is a prospective multi-center study of a new diagnostic test for microsatellite analysis (MSA) for bladder cancer. This study will identify the temporal performance characteristics of urinary sediment MSA and determine the sensitivity and specificity in detecting bladder cancer in participants requiring cystoscopy. Additionally, this study will establish which of the 15 individual markers or combination of markers that comprise the MSA test are most predictive of the presence of bladder cancer.

Sponsor and Principal Site – Johns Hopkins University and Health and Human Services, NIH
Site Principal Investigator – Guido Dalbagni, MD

IV. A Prospective Study of Quality of Life in Patients Undergoing Total Pelvic Exenteration

The purpose of this study is to characterize the extent of physical and psychological stress, and overall quality of life in patients undergoing total, anterior or posterior pelvic exenteration (surgical removal of the colon, rectum and bladder and in women, the reproductive organs as well). Results of this study (which include patients undergoing surgery for gynecologic and colorectal cancers, as well as urological cancer) would potentially be utilized to generate a preoperative tool that would accurately predict patients' response to surgery and aid in the selection of appropriate candidates for surgery and utilize early intervention to potentially alleviate specific stressors.

Sponsor – Memorial Sloan Kettering Cancer Center
Principal Investigators – Bernard Bochner, MD and Dennis Chi, MD

V. Phase II Trial of Gemcitabine, Carboplatin, and Bevacizumab in Chemotherapy Naive Patients with Advanced/Metastatic Urothelial Carcinoma

This is a phase II trial of gemcitabine, carboplatin, and bevacizumab chemotherapy in chemotherapy naive patients with advanced or metastatic urothelial transitional cell carcinoma (TCC). The objectives are to define the safety of this combination chemotherapy regimen and evaluate the response rate and time to disease progression.

Sponsor – Genentech, Memorial Sloan Kettering Cancer Center
Principal Investigator – Dean Bajorin, MD

Ask the Doctor



Mark Soloway, MD, FACS, Professor and Chair, Department of Urology, Miller School of Medicine, University of Miami, was kind enough to answer our questions for this issue of Outlook.

Q. There has been some discussion about substituting the term “superficial bladder cancer” with other terms. Why is that and what are some of the alternate suggestions?

A. The primary problem with the term "superficial" bladder cancer is that it has little real meaning. Superficial is defined by

the dictionary as lying on, not penetrating. As currently used, superficial includes very low grade tumors which are confined to the surface or inner lining of the bladder (referred to as Ta) as well as high grade tumors which invade into the first layer called the lamina propria (labeled as T1). T1 tumors have the potential to spread and many times are deeper into the wall than we initially think. Thus the low grade Ta (confined to the surface) tumors have a different biologic implication than those that invade. These two types of tumors are two different animals and should not be grouped into a single category. Thus, we should eliminate the term "superficial" from our urology lexicon when it is used to describe a bladder tumor. Effective treatment begins with proper staging and an accurate dialogue with the patient and our colleagues. I believe that, to be on the same page, we must be accurate with our definitions.

Q. What can you tell us about the NMP22 test as a screening device? Do you recommend it? Can it be used alone or is it best used in conjunction with other screening tests?

A. The bladder tumor markers such as the NMP22 have roughly the same accuracy as PSA for the early detection of prostate cancer. PSA detection has dramatically altered the stage at which prostate cancer is currently diagnosed compared to 20 years ago before we had this indicator. Similarly if all of those with a cigarette smoking history or exposure to another carcinogen were monitored on a regular basis with a marker for the presence of a bladder cancer we might have the opportunity to detect life threatening bladder cancers at an earlier stage.

NMP22, like other products present in the urine in higher quantities in those with a bladder tumor than in those without a tumor, provides the opportunity to help with early detection. NMP22 is not the only such marker. Others such as Immunocyt add the benefit of looking at the cells for abnormal microscopic characteristics. The BTA test is another FDA approved urine based marker that is approved for the detection of bladder cancer.

Whether these tests should be used for patients with an established diagnosis of bladder cancer in an effort to diminish the use of cystoscopy is unclear and urologists are considering the tradeoffs involved in such a decision. These markers, like PSA, are not perfect. An individual may have a bladder tumor and the marker may not detect any abnormality or the test may read negative.

Q. In some cancers, the longer a patient goes without a recurrence indicates that there will be no recurrence of his

or her disease. Is the same true of bladder cancer, or is a recurrence inevitable?

A. The carcinogen that often if not always causes bladder tumors may have caused an irreversible change in the bladder and thus will rear its head and induce a malignant change at any time. Thus, once an individual has a bladder tumor they are subject to a subsequent tumor which may be a true recurrence of the initial tumor or more likely a new tumor not related to the first, quite similar to skin cancers caused by exposure to the sun years before. Thus, there is the need for life long monitoring although the frequency of monitoring can be lessened as a longer interval between tumors is evident.

Volunteer Corner



BCAN's National Volunteer Board (NVB) held its first meeting on September 18, 2006. The NVB, which meets monthly via teleconference, brainstorms and shares ideas for local bladder cancer awareness activities, local fundraising opportunities and best practices for recruiting new volunteers. The board will also be responsible for establishing policies and guidelines for BCAN volunteer activities in communities across the country.

Chaired by Allison Smith, the NVB is comprised of nine survivors and/or family members all committed to furthering BCAN's mission. The board's first project was to develop a press release in support of National Bladder Health Awareness Week (November 12-18), to educate the medical community and general public about bladder cancer symptoms and the importance of early detection, which is a key board initiative. The press release will be made available to anyone interested in sending it out to the media in their local communities. Contact Allison if you would like further information.

The success of the NVB is largely dependent upon recruiting others to help with this grass roots effort. Below is a list of the board members, their locations and email addresses. Anyone who resides in these areas and is interested in joining in our efforts should contact the local board representative:

Allison Smith	Capital Region, New York	allisonsmith@nycap.rr.com
Christine Gray	Albuquerque, New Mexico	cgray266@msn.com
Cindy Thomas-Duffy	Bloomington, Indiana	ciaduffy@indiana.edu
Diana Shaw	Los Angeles, California	shawhouse@earthlink.net
Karen Godfrey	Southwest Florida	kgodfrey@swfla.rr.com
Kim Vennard	New Jersey/metro NYC	kim_vennard@hotmail.com

Pat Screeden	Chicago, Illinois	screeden4@bellsouth.net
Paul Reeves	Atlanta, Georgia	reeves1@bellsouth.net
Rosemarie Ambros	Ruther Glen/Richmond, VA	BVMWorld@aol.com

It's Complementary



Since the mid-1990s Americans have tripled their spending on probiotic supplements. In fact, probiotics is being researched more aggressively today than ever before as a complementary technique relative to a variety of illnesses. According to The National Center for Complementary and Alternative Medicine (NCCAM), scientific understanding of probiotics and their potential for preventing and treating health conditions is at an early stage but moving ahead.

What are probiotics?

Probiotics, referred to as friendly or good bacteria, has been defined by the United National Food and Agricultural Organization and the World Health Organization, as “live microorganisms, which, when administered in adequate amounts, confer a health benefit on the host.” Common foods containing probiotics are yogurt, fermented and unfermented milk, miso, tempeh and some juices and soy beverages. In those foods and in probiotic supplements, the bacteria may have been present originally or added during preparation. Most often they come from two groups of bacteria, Lactobacillus or Bifidobacterium. Within each group are different species and within each species, different varieties.

Friendly bacterial are vital to proper development of the immune system, to protect against agents that could cause disease and to the digestion and absorption of food and nutrients. Interaction between a person and the microorganisms in his or her body and between the microorganism themselves can be crucial to a person's health and well-being.

This bacterial balancing act can be thrown off in two major ways:

- By antibiotics when they kill friendly bacteria in the gut along with the unfriendly bacteria and;
- By “unfriendly” microorganisms such as disease-causing bacteria, yeasts, fungi and parasites.

Encouraging Results

According to a report issued following a conference in 2005 that was co-funded by NCCAM and the American Society for

Microbiology, the following areas have noted encouraging evidence from study of specific probiotic use:

- To reduce recurrence of bladder cancer www.blcwebcafe.org (referring to trials conducted in Japan);
- To treat diarrhea;
- To prevent and treat urinary or reproductive system infections;
- To treat irritable bowel syndrome;
- To shorten the length of an intestinal infection that is caused by a bacterium called *Clostridium difficile* and;
- To prevent and manage atopic dermatitis in children.

In terms of treating cancer, it has been hypothesized that probiotic cultures might decrease the exposure to chemical carcinogens by (a) detoxifying ingested carcinogens; (b) altering the environment of the intestine and thereby decreasing populations or metabolic activities of bacteria that may generate carcinogenic compounds; (c) producing metabolic products which improve a cell's ability to die when it should; (d) producing compounds that inhibit the growth of tumor cells; or (e) stimulating the immune system to better defend against cancer cell proliferation.

According to NCCAM, at this time there is limited evidence supporting some uses of probiotics. Better scientific understanding of these tiny forms of life and their effects on people are needed.

However, as with all complementary and alternative medicine methods, if you are thinking about using probiotic products as part of your health care regime, consult your health care provider first.
