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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.

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President's Message



Dear Friends,

We celebrated BCAN's first anniversary on Sunday, June 25 in Washington, D.C. at the home of Toni and Dwight Bush with over 80 friends and supporters of BCAN. The event—BCAN's first official fundraiser – was very successful as we received more than \$26,000 in contributions. Bob Schieffer, anchor of the CBS Evening News, and moderator of Face the Nation, joined us for the celebration. Bob is a bladder cancer survivor and a good friend and supporter of BCAN. Bob spoke of the importance of raising awareness about bladder cancer and emphasized the need for people to get annual medical checkups, and see a urologist if any suspicious symptoms appear. A big thank you to Bob and Pat Schieffer for joining us, as well as to Toni and Dwight for hosting such a lovely event.

Prior to our anniversary celebration, BCAN was warmly received at the Annual Meeting of the American Urological Association (AUA) in Atlanta in late May and at the Annual Meeting of the American Society of Clinical Oncologists in early June. We connected with hundreds of doctors, researchers, industry representatives, and cancer advocates who are extremely supportive of our efforts to bring attention to bladder cancer issues.

As we enter our second year, our focus continues to be on

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H. Barton Grossman, M.D., FACS
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Johns Hopkins Medical Institutions

William U. Shipley, M.D., FACS
Harvard Medical School and
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

increasing public awareness of bladder cancer. We recognize that volunteer involvement is essential to our achieving this mission. We have recently created a National Volunteer Board, whose members represent various regions of the U.S. This Board will be chaired by Allison Smith, a volunteer from New York, and will be responsible for establishing policies and guidelines for BCAN volunteer activities in communities across the country. The Board, which will meet monthly via teleconference, will brainstorm and share ideas for local bladder cancer awareness activities, local fundraising opportunities, and best practices for recruiting new volunteers.

We are also providing new support services for bladder cancer survivors. On **Saturday, September 9, 2006**, BCAN and the AUA Foundation are co-sponsoring a program for survivors and their families entitled "***Living with Bladder Cancer; Treating, Understanding, Coping.***" This forum—the first of its kind for bladder cancer -- will be held at the AUA headquarters near the Baltimore-Washington Airport from 9:30 a.m. to 1:30 p.m. Whether newly diagnosed with bladder cancer, or in treatment for some time, this forum is designed to give survivors and their families a complete overview of the disease, new treatment options and coping mechanisms. The forum is free and lunch will be provided. Pre-registration is required. For more information, or to register, go to UrologyHealth.org.

The University of Michigan Comprehensive Cancer Center and Department of Urology has sponsored a Bladder Cancer Support group for many years. This group meets quarterly at the Main Hospital at the University of Michigan. The next meeting is **Sunday, September 10**, from 1:00-2:30 p.m. I am honored to have been invited as the guest speaker for this support group meeting, and I will be talking about "Working Together to Increase Public Awareness of Bladder Cancer -- You Can Make a Difference." For additional information about this support group, please contact Nancy Rodriguez-Galano or Phil Rupp at the University of Michigan, 734-615-0564.

In addition, I am pleased to report that George Washington University Hospital in Washington, D.C. is "restarting" its bladder cancer support group this fall. BCAN will be working with GW to help get the word out about this group. The first meeting is scheduled for **Saturday, September 16** from 10:30 a.m. until 12:00 noon, in Ross Hall at 23rd and Eye Streets, NW, Washington, D.C. The room number will be posted at the front desk. For more information, please contact Ted Billings at 202-232-2001 or Ted_Billings@comcast.net.

We've made some updates to our website, www.bcan.org, and

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University of Chicago

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

Gary D. Steinberg, M.D., FACS
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Disclaimer:

The information and services provided by the Bladder Cancer Advocacy Network (BCAN) are for informational purposes only. The information and services are not intended to be substitutes for professional medical advice, diagnosis or treatment. If you are ill, or suspect that you are ill, seek professional medical attention immediately! BCAN does not recommend or endorse any specific physicians, treatments, procedures or products even though they may be mentioned in this newsletter.

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Advocacy Network

I invite you to check it out:

- On the “Clinical Trials” page, we have a new link to current bladder cancer clinical trials compiled by the National Cancer Institute, and a new “Trials to Note” section that provides easy-to-understand descriptions of several current trials that are actively recruiting patients.
- Several additions have been made to the “Resources” page, including a direct link to a pamphlet published by the National Comprehensive Cancer Network and the American Cancer Society entitled “Bladder Cancer -- Treatment Guidelines for Patients.”
- We’ve added an “Events” page as well as a “Press Room.” If you are hosting or sponsoring an event, or know of an upcoming event which would be of interest to bladder cancer survivors and their families, please forward the information to us at info@bcan.org and we will be happy to post it.

We are looking forward to increasing our activities and our resources during the coming year. We are grateful for your continued support of BCAN and our mission.

Many thanks again to Dale Heffler, BCAN volunteer and editor of BCAN Outlook.

Diane Zipursky Quale

On Trial



For this issue of BCAN Outlook, we are providing information about two clinical trials at MD Anderson Cancer Center in Houston. For more information about these trials, or other clinical trials in the Department of Urology at M.D. Anderson Cancer Center, contact **Nancy Ainslie, BCLS, RN, research nurse manager, at (713) 792-3250.**

1. Phase III Study of Hexvix Fluorescence Cystoscopy and White Light Cystoscopy

H. Barton Grossman, MD, Department of Urology, The University of Texas M. D. Anderson Cancer Center, Houston, is the Principal Investigator of an international study comparing conventional (white light) and fluorescence cystoscopy in bladder cancer.

Fluorescence cystoscopy is performed by instilling a drug (Hexvix) in the bladder and retaining it for 1 hour prior to the planned cystoscopy. After exposure to Hexvix, bladder cancer cells accumulate protoporphyrin IX, a natural precursor to

blood. This protein fluoresces red when exposed to blue light, making bladder cancers easier to detect.

Hexvix is currently approved for use in Europe and fluorescence cystoscopy with Hexvix has been shown to increase the ability to detect bladder cancer. This randomized study will evaluate the ability of fluorescence cystoscopy to increase the rate of bladder cancer detection and decrease the rate of tumor recurrence.

Participating international institutions include:

Baylor College of Medicine, Houston
Boston University School of Medicine
Cedars-Sinai Medical Center (Los Angeles)
Centre Hospitalier Universitaire de Québec
Duke University Medical Center
The Emory Clinic
Johns Hopkins Medical Institute
Kingston General Hospital (Kingston, Ontario, Canada)
Mayo Clinic Rochester
Mount Sinai Medical Center (New York)
Stanford Cancer Center
Thomas Jefferson Medical College (Philadelphia)
University of Miami School of Medicine
University of Rochester Medical Center (NY)
The University of Texas
M. D. Anderson Cancer Center (Houston)
Urological Institute (Beachwood, Ohio)
VA Medical Center (Gainesville, Fla)
Vanderbilt University Medical Center

2. Intravesical Ad-IFN- α /Syn3 Therapy for BCG-Refractory Superficial Bladder Cancer

This is a phase I clinical trial of adenoviral mediated interferon- α gene therapy administered with the enhancer Syn3 (Ad-IFN α /Syn3) in patients with papillary Ta bladder cancer, or carcinoma in situ that is refractory to BCG. Patients who have persistent bladder cancer despite 2 courses of BCG or BCG plus interferon- α are eligible.

The primary objective of the trial is to evaluate the safety and tolerance of Ad-IFN/ α Syn3. Although this is a phase I study, the clinical response to Ad-IFN α /Syn3 will be evaluated by cystoscopy and biopsy and cytology. Those patients with a complete response, that is, a negative cystoscopy, biopsy, and cytology (no evidence of cancer cells) will be eligible for a second course of treatment at the same dose. Urine IFN- α will be measured during therapy, and the levels achieved in these

patients may be particularly informative for future studies.

The trial is supported by the NCI Genitourinary SPORE in Bladder Cancer and the Principal Investigator is Colin P. N. Dinney, MD, Department of Urology, The University of Texas M. D. Anderson Cancer Center. Co-Principal Investigator is Michael O' Donnell, MD, Department of Urology, University of Iowa.

Ask the Doctor



We thank Walter Stadler, MD, FACP, Professor and Director of Genitourinary Oncology at the University of Chicago, for answering our questions for this issue of BCAN Outlook.

Q. What are the most important things for a person with metastatic bladder cancer to know?

A. It is important for people with metastatic bladder cancer (bladder cancer that has spread to other parts of the body) to be aware of the best treatment options available to help fight this disease. Currently, there are two chemotherapy regimens that have become the standards of care for metastatic bladder cancer—MVAC (methotrexate, vinblastine, adriamycin, and cisplatin) or gemcitabine/cisplatin. Because cisplatin may be difficult to administer in patients with abnormal renal function, carboplatin based therapy can be considered, but the data strongly suggest that carboplatin is inferior to cisplatin. As a reasonable alternative to account for renal insufficiency and still provide maximal benefit, some have considered the combination of gemcitabine, carboplatin, and paclitaxel, however, at this time there is no phase III data to validate efficacy.

Because patients with organ metastases, symptoms from their metastatic cancer, or anemia as a result of their cancer do more poorly, participation in a clinical trial should always be considered. For patients who suffer from progressive cancer following initial therapy, there is no good standard care and participation in a clinical trial should be strongly considered.

Q. What is the difference between neo-adjuvant chemotherapy and adjuvant chemotherapy? Is there an advantage to one over the other?

A. Neoadjuvant chemotherapy is administered *prior* to surgery for muscle invasive bladder cancer. Completed phase III trials show that cisplatin based multi-agent chemotherapy (generally MVAC, but gemcitabine/cisplatin is a reasonable alternative)

improve survival when administered in this manner.

Adjuvant chemotherapy is administered *after* surgery. The agents probably work just as well, but the completed trials are too small to definitively prove this. The *disadvantage* of adjuvant therapy is that chemotherapy following major surgery is harder to tolerate than it is prior to surgery. The *advantage* of adjuvant therapy is that complete pathologic staging information (available only after surgery) provides better information regarding prognosis, which can better inform the patient and the doctor on the relative value of chemotherapy.

In other words, if the risk of recurrence of bladder cancer based on complete pathologic information is very high, a relatively modest chemotherapy benefit (e.g. a 10% improvement) will lead to a very large absolute benefit. However, the absolute benefit of chemotherapy is much lower when the overall risk of recurrence is less.

Volunteer Corner



Christine Gray of is one of BCAN's newest volunteers. While bladder cancer is often referred to as an "old man's disease", Christine's experience proves that isn't necessarily true. Here is her story.

I was 27 years old in November 2004 when my husband and I found out that we were pregnant. It was such an exciting and joyful time for us. However, in December I had an ultrasound in which my doctor found a mass in my bladder. He sent me to a urologist, who was very concerned. What was supposed to be the happiest times in our lives became one of the most frightening.

The doctor couldn't understand why I didn't have blood in my urine so he sent me for a more extensive ultrasound. After the holidays, we spoke with my urologist and he performed a cystoscopy. Not liking what he saw, he decided to do a TURB, but we needed to wait until I entered my second trimester. So in February I went in the hospital for a TURB and they removed the mass. Later that week my doctor called and told me it was a TA superficial tumor. He then told me that this is so rare for someone my age that the pathologists kept looking over the results to make sure it wasn't a mistake.

Because of my pregnancy, my doctor decided not to do any more scopes until after my daughter was born. I went for the first one in August of 2005 and everything was fine. I then had

to go for an x-ray of my kidneys, which also was a very frightening experience. I'm one of the lucky ones though. My single tumor was low-grade and non-invasive. After one surgery, I'm doing fine. However, with a 70% rate of recurrence, bladder cancer survivors must remain vigilant. For me this means quarterly cystoscopies.

Until this happened to us, we never heard of anyone with bladder cancer. I think we need to make people aware of this silent but deadly cancer. They need to know that if detected early and treated, the chances of someone beating it are great.

Women particularly need to be informed and educated about this disease, because women as a group are just not aware of the symptoms and are being diagnosed too late. I know I will battle this cancer the rest of my life, but if my story can help any others out there, I will gladly shout it from the roof tops.

It's Complementary



Tai chi is an ancient Chinese martial art. It is becoming increasingly popular around the world, both as a basic exercise program and as a complementary form of medicine, producing such health benefits as stress reduction, greater balance and increased flexibility, especially for older adults.

Tai chi hasn't been studied scientifically until recently. However, preliminary research shows that for older adults in particular, practicing tai chi regularly may:

- Reduce anxiety and depression
- Improve balance and coordination
- Improve sleep quality
- Slow bone loss in women following menopause
- Reduce high blood pressure
- Improve cardiovascular fitness
- Relieve chronic pain
- Improve everyday physical functioning

In fact, according to the American Cancer Society, tai chi is recognized as an exercise that provides the same cardiovascular benefits as moderate exercise, such as lowered heart rate and blood pressure.

A person doing tai chi moves his or her body slowly and gently, while breathing deeply and meditating. In tai chi, each movement flows into the next, with the movements performed gently and at uniform speed. When doing tai chi, it is considered important to concentrate, putting aside distracting

thoughts and breathing in a deep, relaxed and focused manner.

The National Center for Complementary and Alternative Medicine is sponsoring a number of studies to find out more about tai chi's effects, how it works and diseases and conditions for which it may be most helpful. Two studies on how tai chi might affect cancer patients focus on:

1. Tai chi compared with cardiovascular exercise fitness programs in terms of improving physical fitness and endurance, reducing stress and improving well-being in adult cancer survivors
2. Tai chi for women recently diagnosed with breast cancer to see if helps them cope better, have less stress and an improved immune system and quality of life

Although tai chi is considered to be relatively safe, before beginning a program that involves movement of joints and muscles, talk with your health care provider. For more information, visit www.nccam.nih.gov or www.cancer.org