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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,

We welcome in the new year, which we know will be full of opportunities for BCAN and our growing network of supporters and survivors.

We are continuing our efforts to provide educational information to the bladder cancer community. We are especially pleased to invite you to participate in a free telephone education workshop entitled, **“Medical Update on Bladder Cancer”**, on **February 7, 2007, from 1:30-2:30 p.m. Eastern Standard Time**. This workshop is hosted by CancerCare, a national nonprofit organization whose mission is to provide free, professional support services to anyone affected by cancer. This workshop is presented in partnership with BCAN, along with many other patient and professional organizations. Dr. Walter Stadler, University of Chicago, Dr. Michael O'Donnell, University of Iowa (both members of BCAN's Scientific Advisory Board), and Joanne Walker, certified ostomy nurse from Johns Hopkins will be on the expert panel. While the program is free, registration is required. Please visit our homepage, [www.bcan.org](http://www.bcan.org) for registration information. This program is made possible by a charitable contribution from Bristol-Myers Squibb Oncology.

Given the success of our first bladder cancer patient forum last September in the Baltimore-Washington area, BCAN is “taking the show on the road”—to sunny Florida! On **Saturday**,

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University of Southern California,  
Norris Comprehensive Cancer Center

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

Walter Stadler, M.D., FACP

**March 17, 2007**, BCAN is once again partnering with the American Urological Association Foundation in hosting the patient forum “**Living with Bladder Cancer; Treating, Understanding, Coping.**” The program will be held at the Business Building of Florida Atlantic University in Boca Raton, Florida, from 9:30 a.m. to 1:30 p.m. We are honored to be working with Dr. Mark Soloway, Professor and Chairman of the Department of Urology, along with other physicians from the University of Miami Sylvester Comprehensive Cancer Center and Miller School of Medicine, who will be serving as our panel of experts for this forum. Topics to be covered include bladder cancer basics; whether smokers should be screened for bladder cancer; treatment options for non-invasive bladder cancer; bladder removal and reconstruction; and research initiatives in bladder cancer. The forum is free and lunch will be provided. We encourage bladder cancer survivors and family members in the South Florida area to join us—and anyone else who is interested in coming to Florida for some warmth and sunshine. Pre-registration is required. Please visit [www.bcan.org](http://www.bcan.org) for registration information.

I hope that many of you have already seen the article about bladder cancer in the Winter 2006 issue of **CURE** magazine (Cancer Updates, Research & Education). This comprehensive article, entitled “**Bladder Cancer: Breaking the Research Barrier**”, addresses the need for doctors and patients to work together to change the status quo in bladder cancer treatment. The article provides an overview of the diagnostic and treatment tools currently available for bladder cancer, and highlights the need for improved treatments for all stages of the disease. BCAN is identified in the article as the first national advocacy group for bladder cancer and is included as a resource for the bladder cancer community.

As BCAN enters its second full year of operation, I want to thank all of our generous donors whose support makes it possible for us to continue our efforts to raise awareness about bladder cancer, provide educational resources to the bladder cancer community and work toward increasing research directed at improving treatments and outcomes for the disease. We are especially grateful to the families who have lost loved ones to bladder cancer or other diseases and have asked that memorial contributions be made to BCAN. We are honored to be pursuing our mission in memory of Benjamin Astley, Esther Bush, Nelson DeVore, Arnold Dompieri, Patrice Hitt, Herbert Kirshman, Carlos Tejeda and Paul Wonek. Our thoughts are with their families.

*Diane Zipursky Quale*  
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## On Trial



We thank John P. Stein, MD, Associate Professor, Department of Urology, Norris Comprehensive Cancer Center, University of Southern California, Keck School of Medicine, for providing us with the following information about a bladder cancer trial at his institution.

### **Randomized clinical trial comparing the orthotopic T-pouch ileal neobladder versus the orthotopic Studer pouch ileal neobladder.**

All patients with a history of bladder cancer undergoing radical cystectomy at the University of Southern California, Keck School of Medicine and the Norris Comprehensive Cancer Center and who are appropriate candidates from an oncologic and clinical perspective are offered this clinical trial which evaluates the early and long term clinical effects of two different orthotopic neobladders (T-pouch, Studer pouch). Specifically the radiographic evaluation and upper tract function will be evaluated as these reservoirs differ in respect to the antireflux mechanism. The T-pouch is a flap-valve technique while the Studer pouch maintains an isoperistaltic mechanism. There are currently more than 300 patients in the study, which has a target of 500 patients.

## Ask the Doctor



For this issue we thank Michael O'Donnell, MD, FACS, Holden Cancer Center, University of Iowa Hospital, for answering our questions. Remember, if you have questions you'd like answered, e-mail them to [info@bcan.org](mailto:info@bcan.org).

**Q. Please explain how the FISH test works. Which patients would benefit from its use? Should it be given as a matter of routine? If so, in addition to cytology and/or cystoscopy or should it stand on its own?**

**A.** FISH stands for Fluorescent In Situ Hybridization. It is a technique that uses colored DNA probes to count the number of certain chromosomes or specific chromosomal regions in individual cells derived from the bladder lining. The thought is that cancer cells go haywire as they start growing aggressively and as a result start making major mistakes in replicating their chromosomes and DNA.

The final FISH result comes out as NORMAL, ABNORMAL, or INCONCLUSIVE and is based on meeting predetermined thresholds for the number of abnormalities seen. Inconclusive tests occur when there are insufficient total cells for analysis, contamination, or abnormal results right on the borderline.

As with many new tests, the first results that came out with FISH tended to over exaggerate its performance. Initially it was reported that FISH tests picked up over 85% of all bladder cancers (sensitivity of over 85%) and was fairly accurate in its results (specificity of 96%). More recent “real world” reports, however, suggest sensitivity closer to 75% and a specificity in the 70-80% range. The practical result of these performance characteristics is that a normal (or negative) FISH test does not rule out cancer. Similarly, an abnormal (or positive) FISH does not mean someone has cancer. As a comparison, a positive cytology test for high grade cancer is right about 95% of the time. The problems with cytology are that it is highly dependent on how good the pathologist is. Cytology still fails to detect over 50% of all bladder cancers.

Does that mean that the FISH test is worthless? No, it means that the LIKLIHOOD of cancer is increased or decreased by an abnormal or normal FISH test, respectively. As such, the FISH test cannot be used in isolation but rather should be used in the context of all the other clinical data including the results of cystoscopy and cytology.

Another vexing issue with an abnormal FISH test is that it may “anticipate” the recurrence of bladder cancer by many months before a tumor can be found. This has been referred to as an “anticipatory positive” FISH. Unfortunately, areas in the bladder that have been subject to years of carcinogen exposure (e.g. from smoking) may already have abnormal chromosome signatures yet are still insufficient to be true cancer. This is commonly referred to as dysplasia. This would explain why many patients with abnormal FISH tests still don’t have cancer but remain at higher risk to eventually develop it.

Since the FISH test is still so new, many urologists have not figured out just how to incorporate it into their practices. Also, the FISH test is quite expensive (often more than \$500 per test) so it should not be used haphazardly.

**Q. What are the treatment alternatives for a bladder cancer patient who does not respond to BCG?**

**A.** With bladder cancer treatment, the devil is always in the details. Patients may “fail” BCG in many different ways, the

exact circumstances of which help determine the best next course of action. Patients may have recurrent cancer at the first post-treatment cystoscopy/cytology or they may relapse at a much later date. They may fail one 6-week course, more than one course, or while on active maintenance therapy. They may fail with low-grade disease or high-grade disease. Patients may also fail simply because they cannot tolerate the BCG at the current treatment regimen. However, despite all these nuances, there are several general guidelines for subsequent therapy:

(1) Any patient with high-grade disease, especially invasive stage T1 or CIS, who shows actual worsening of disease in stage, grade or extent while on BCG therapy should be considered for radical therapy early (i.e. cystectomy). This usually signifies a very aggressive subtype of bladder cancer. If medically unfit, alternative treatment (discussed below) can be considered.

(2) Any patient with high-grade disease who fails two back-to-back courses of BCG should also be strongly considered for cystectomy.

(3) Most patients who show some progress with the first course of BCG should be re-treated with another course of BCG as up to half will obtain a complete response. Higher risk patients with high grade stage T1 or CIS should especially consider the addition of the immune augmenting agent interferon with the next course of BCG. A second course of BCG can be dose reduced to 1/2 or 1/3rd of usual dose, improving its tolerability.

(4) Patients relapsing after one course of BCG without stage or grade progression are also good candidates for more BCG with or without interferon. Patients relapsing after two or more prior courses of BCG should only be considered for retreatment (recommend BCG with interferon) if the timing between relapses is one year or greater.

(5) Patients relapsing or failing BCG with low volume, noninvasive, low grade papillary bladder cancer rarely need to come to cystectomy at the next step and should be considered for alternative treatments.

(6) Patients felt to be intolerant to BCG can often be helped by substantially lowering the BCG dose (to 1/3 or 1/10th), spreading out the treatments 2 weeks apart, reducing the dwell time to as little as 30 minutes, or providing fluoroquinolone antibiotics 6 and 18 hours after each treatment.

(7) In general, single agent conventional intravesical chemotherapy (mitomycin, thiotepa, adriamycin) is ineffective

after BCG failure with less than 20% long term disease free rate.

(8) Newer intravesical chemotherapy agents such as gemcitabine or docetaxel are showing activity in patients previously failing BCG, especially in the form of combination sequenced therapy, e.g. gemcitabine X 1.5 hours followed immediately by mitomycin X 2 hours. However, these strategies remain investigational at present and are not yet considered standard therapy. Consult a specialist urologist in this field before considering them.

(9) Patients with high grade, stage T1 or CIS wishing to retain their bladders after 2 or more failures of a BCG program need to realize that there is a proportionately increased risk of progression to potentially lethal disease with further delay. There is no completely safe window during the time investigational therapy is being tried. The risks of progression per 3-month quarter may be up to 5% with each 3-month delay.

**Q. Why does bladder cancer have such a high recurrence rate?**

**A.** Superficial (non muscle-invasive) bladder cancer does have one of the highest recurrence rates of any solid cancer, upwards of 70% within 5 years. There are at least 4 reasons responsible for this high rate of recurrence:

(1) Not all tumors are found during the planned conventional white light cystoscopy and resection (TURB). An additional 20% are seen under blue-light cystoscopy using an enhancing dye placed into the bladder beforehand. This technique is currently under investigation for FDA approval in the U.S. Also, for more invasive stage T1 tumors there is a 30% or higher chance of missing true muscle invasion and a greater than 50% of leaving residual cancer behind. For this reason it is recommended that most stage T1 tumors be re-TURB'd within 4-6 weeks.

(2) Tumors may re-implant after TURB. Like dandelion seeds they may re-attach to new areas and start new tumors. The most effective way to prevent this is for the urologist to administer a chemotherapy drug like mitomycin into the bladder within 6 hours of every TURB.

(3) Intravesical drugs such as chemotherapy or BCG may fail to eliminate microscopic focuses of cancer that are too small to be seen. Higher concentrations of chemotherapy drugs (same dose in smaller volume) and minimizing dilution, newer drugs, and combination strategies may help this.

(4) The diseased bladder from years of carcinogen exposure may let brand new cancers emerge over the course of time. Maintaining a healthy lifestyle including quitting smoking remains an important first step patients may take in reducing recurrence. There is also some evidence that high dose antioxidant vitamins will assist in this regard. A true chemopreventative drug, however, has not yet been found.

## Volunteer Corner



Paul Reeves has been an active volunteer with BCAN since shortly after it started and serves as a member of its National Volunteer Board. He is currently working toward his goals of increasing awareness of bladder cancer in his home state of Georgia and helping other bladder cancer patients in any way that he can. Here is Paul's story:

My first symptoms of bladder cancer, in 2001, were similar to those of a urinary tract infection - urinary discomfort, frequency and urgency. I visited my urologist, who performed a sonogram test and diagnosed my problem as retention of urine due to scar tissue from a previous prostate surgery. He prescribed Flomax. During my next appointment, he performed a cystoscopy, which revealed nothing amiss. I asked to have a urine sample sent to a lab. After several days I got the call - the test was positive for bladder cancer. Diagnosis after biopsy: Superficial bladder cancer, CIS, stage Ta, high-grade.

I began a series of BCG treatments which didn't work, so I then had a series of BCG +interferon treatments. This time all tests came back negative. After several series of BCG+Interferon maintenance treatments, my doctor stopped the treatments. I soon had a recurrence. I asked for tests to be made of my upper tract as well as my bladder and these tests indicated suspicious cells coming from both my kidneys and my bladder.

At this point I was getting a little worried. I posted my situation to the Bladder Cancer WebCafe Support site and soon got a response from a list member who had experienced my same situation. He had been successfully treated by Dr. Michael O'Donnell. I contacted Dr. O'Donnell, who explained the options he thought were appropriate for my situation and then I traveled from Georgia to the University of Iowa for 6 weeks of BCG+Interferon treatments to the upper tract and the bladder, since I had responded to this combination once before. Subsequent tests showed I was still positive for bladder cancer.

Dr. O'Donnell next recommended intravesical treatments with a combination of gemcitabine and mitomycin over a six-week period. This time all tests were negative. It was close to Christmas 2004 and I was thankful for this great gift. Monthly maintenance treatments were performed locally for six months, then were stopped when all tests continued to be negative. Unfortunately, the cancer recurred again about six months later.

I had another consultation with Dr. O'Donnell and he outlined my options, one of which was six more intravesical treatments with docetaxel and mitomycin, a different chemical combination. Six of these treatments were completed, and the test results were negative. Monthly maintenance treatments identical to the first six were prescribed and I have completed two of these to date, with 10 more to go. I will be retested periodically throughout this period.

Throughout my fight with bladder cancer, I have tried to maintain a pro-active partnership with the doctors and clinics that have treated me. I have asked a lot of questions and have kept myself well informed through BCAN, the WebCafe list, and personal research.

As I recovered from the initial shock of learning I had bladder cancer, and found that my past use of tobacco was probably the cause, I wondered how many millions of people are still at risk for bladder cancer and who know as little as I did. Initially, I could find no organized effort to increase public awareness about bladder cancer. I resolved to try to salvage something good out of my bad experience. However, my impact was small, as it was limited to people I knew and met and who showed an interest. Thankfully, within the past year, BCAN has provided a vehicle for me to become involved in a more meaningful way. I will continue to remain active as a volunteer for this fine organization, doing what I can to help others detect and defeat bladder cancer.

### It's Complementary



Yoga is an ancient Indian science that has been practiced for hundreds of years. It incorporates various postures, breathing techniques, imagery, meditation and relaxation techniques, with the ultimate goal of reaching complete peacefulness in body and mind. While there has been no specific link to the benefits of yoga relative to bladder cancer, many complementary medicine enthusiasts are convinced that, due to the mental and physical aspects of yoga, it may be particularly

useful for people battling many types of cancer, either early in the diagnosis and treatment process or in long-term survival.

According to an article in **COPING** by Kavita Chandwani, MD and Lorenzo Cohen, PhD, of the University of Texas M.D. Anderson Cancer Center, the first study of yoga in people with cancer was conducted in India and found it was useful in improving quality of life during radiation treatment and for some time immediately after completion of treatment. In another study that provided group support, meditation, visualization, imagery and stretches, people with cancer experienced lower total mood disturbance and decreased overall distress compared to those in the comparison group.

Similarly, a study conducted at the University of Texas M.D. Anderson Cancer Center, which examined the benefits of yoga from the Tibetan tradition for people with lymphoma, found that the yoga group reported lower overall sleep disturbances during the follow up period than did the comparison group. Participants practicing yoga had better sleep quality, less difficulty falling asleep, slept significantly longer and used fewer sleep medications than did those in the comparison group.

Hatha yoga, the most popular form, focuses on physical poses and controlled breathing. In a typical hatha yoga class you might learn anywhere from 10 – 30 poses. Controlled breathing can help control your body and gain control of your mind. In addition to a good means of relaxation and stress release, other health benefits of yoga include increased flexibility; management of chronic health conditions, such as asthma, carpal tunnel syndrome, depression, low back pain, osteoarthritis of the knees or memory problems; weight loss and balance.

Drs. Chandwani and Cohen write that yoga may be particularly useful for people with cancer because of its holistic nature—relaxation techniques, meditation, breathing exercises and gentle stretching—can help to facilitate recovery. The lack of negative side effects, and some initial indication of efficacy, makes yoga an attractive stress management technique for people with a variety of illnesses.

*As with any complementary or alternative medicine therapy, talk with your healthcare provider prior to starting a program.*