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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,

BCAN's educational programs for the bladder cancer community continue to be received warmly and with great appreciation. On October 13, we were in Chicago for "**Understanding Bladder Cancer: A BCAN Educational Forum,**" at the University of Chicago. More than 75 survivors, caregivers, and family members attended the program, at which our expert panel addressed a wide variety of issues of interest to the bladder cancer community, and engaged in very interactive question and answer sessions. Following the program, one of the attendees wrote: *"My wife and I thank you for putting on an informative forum this past weekend in Chicago... The knowledge and perspective I gained is invaluable."* Equally important as the educational aspect of this program was the opportunity for the attendees to meet others with bladder cancer, share experiences, and make new friends. As another attendee wrote: *"Just a note to say thank you for a wonderful program. I got as much from being around that many survivors as I did from the speakers."*

BCAN extends its sincere gratitude to Dr. Gary Steinberg, University of Chicago, for putting together such an impressive and talented panel of experts. We are grateful to Dr. Cheryl Lee, University of Michigan; Josephine Silvestre, RN, University of Chicago; Dr. Norm Smith, Northwestern University; Dr. Marcus Quek, Loyola University; Dr. Walter

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University of Miami School of Medicine

Stadler, University of Chicago; and Janice Colwell, RN, MS, CWOCN for sharing their expertise and time with us. We also want to thank our volunteers from the University of Chicago Urology Department whose time and energy were critical to the success of the forum: Laura Kujawa, Victoria Moore and Carol Sullivan, as well as volunteers Connie Meeks, Jim Solomon, and Alec Solomon whose help was invaluable on the day of the event.

Our educational efforts continue in the month of November. We are partnering with the American Urological Association Foundation in hosting two free, one-hour interactive “webinars” on bladder cancer during **Bladder Health Awareness Week. On Monday, November 12 at 8p Eastern**, Dr. Mark Soloway will be speaking on “**Living with Non-Invasive Bladder Cancer**,” and on **Tuesday, November 13 at 8p Eastern**, Dr. Mark Gonzalgo will discuss “**Living with Invasive or Metastatic Bladder Cancer**.” There will be an opportunity for participants to ask questions of the doctors. All that is needed to participate is a computer with internet access and a telephone. Advanced registration is required. Please visit [www.urologyhealth.org](http://www.urologyhealth.org) for more information and to register.

On Sunday, December 2, we are partnering once again with Vital Options International to feature bladder cancer on the Group Room® radio show, a weekly syndicated cancer talk show that is also simulcast on the internet and XM Satellite. This program will address bladder cancer clinical trials. More detailed information can be found on our website in the coming weeks.

Look for our newly-designed website, [www.bcan.org](http://www.bcan.org) in mid-November. The new site will be easier to navigate and will include a number of new features, including “Inspirational Stories,” more comprehensive medical facts and more detailed resources. We are also thrilled to announce that BCAN was awarded a “**Google Grant**” which provides our website with free advertising for a limited time period. We are hopeful that this grant, coupled with our newly-designed website, will greatly improve the traffic to [www.bcan.org](http://www.bcan.org) and promote the continued growth of our community.

Speaking of community, we are ever grateful for the efforts of our volunteers around the country who are helping to raise public awareness of bladder cancer and of BCAN’s mission. We greatly appreciate the continued generosity of our donors whose support enables us to increase our efforts to bring bladder cancer to the forefront of public consciousness, and to provide much needed educational support to the bladder cancer community. In particular, we are especially grateful to the

**Walter Stadler, M.D., FACP**  
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

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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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families who have lost loved ones to bladder cancer and have asked that memorial contributions be made to BCAN. We are honored to be pursuing our mission in memory of Robert Barnard, William Bruin and Paula Smith. Our thoughts are with their families and friends.

*Diane Zipursky Quale*  
*President*



*We thank Dr. Maha Hussain, University of Michigan, for providing us with the following description of an exciting Phase II trial for advanced bladder cancer patients.*

Patients with advanced bladder/urothelial cancer who have achieved stable disease or better with standard chemotherapy are currently being recruited for a phase II, multi-institutional, randomized trial. This trial is pioneering a maintenance therapy approach in the hopes of consolidating the response and delaying disease progression. The title of this trial is *“Randomized Phase II Trial of Maintenance SUO11248 (Sutent) versus Placebo Post Chemotherapy for Patients with Advanced Urothelial Carcinoma”* and is being conducted at the University of Michigan, the Cleveland Clinic, the University of Chicago, Weill Medical College of Cornell University, and the University of California-San Francisco.

In order to be eligible for this study, urothelial cancer patients must have adequate organ function, must have previously received 4-6 cycles of standard chemotherapy and must have achieved disease stabilization or remission. Patients must be enrolled 42 days after receiving the last standard chemotherapy dose. A signed consent form will be required before participation in the study is allowed.

If you meet the eligibility requirements and are interested in joining this important study, please contact the participating institution in your area (listed below) for more information.

**University of Michigan**

Principal Investigator: Maha Hussain, M.D.  
Contact: Cancer AnswerLine 800-865-1125

**Cleveland Clinic**

Co- Investigator: Robert Dreicer, M.D.  
Contact: 216-445-0861

**University of Chicago**

Co-Investigator: Walter Stadler, M.D.

Contact: 773-834-7424

**Weill Medical College of Cornell University**

Co-Investigator: David Nanus, M.D.

Contact: Kristen Petrillo, 212-746-5430;

email: krp9009@med.cornell.edu

**University of California, San Francisco**

Co-Investigator: Jonathan Rosenburg, M.D.

Contact: 415-353-7085

**Ask the Doctor**



*Our questions for this issue of Outlook were answered by Donald Lamm, M.D. of BCG Oncology in Phoenix, AZ. We sincerely appreciate his sharing his opinions and impressions with us.*

**Q. BCG was approved for the treatment of bladder cancer in 1990, and remains the primary intervesical treatment for bladder cancer. Are there new agents on the horizon which may work as well—or even better—than BCG?**

**A.** The success of BCG has been a great help to many patients, but no treatment works for everyone. Even with the optimal BCG treatment schedule, about 20% of patients will fail to respond. With time, many patients who respond will initially fail BCG. Other patients have side effects that prevent them from receiving BCG. All of these add up to as much as 50% of bladder tumor patients who need a treatment other than BCG. That's why new alternative treatments for non muscle-invasive bladder cancer are needed. Unfortunately, when drugs are to be submitted for study to the FDA, they are generally compared with BCG. And because BCG is so effective it is difficult to find something better. In addition, to prove a new treatment is better requires hundreds if not thousands of patients. This becomes financially prohibitive for many companies. Nonetheless, there are some encouraging drugs being developed. Here is a small sampling:

**•Improved Mitomycin Treatment.** While Mitomycin (MMC) is found to be less effective than BCG in many studies, including our Southwest Oncology comparison, significant improvements in MMC are being developed. First and immediately applicable is the optimized MMC schedule: overnight dehydration, alkalization of the urine, careful,

confirmed bladder drainage and concentrated MMC at a dose of 40mg/20ml as described by Dr. Au. This schedule nearly doubles the efficacy of MMC. The second approach is to increase the penetration of MMC into the bladder wall, and this can be done using hyperthermia, electromotive techniques or by the addition of enzymes to increase penetration. All of these techniques are in trials and have the potential of significantly improving the response we see with MMC and other chemotherapies.

•**New Chemotherapies.** Eoquin, a drug related to Mitomycin C, is currently undergoing Phase 3 studies in the U.S. It is reported to be more potent than MMC. Gemcitabine and docetaxel or paclitaxel, drugs known to have efficacy in advanced bladder cancer, are being evaluated as intravesical agents. For patients who fail BCG, these drugs, or more recently drugs in used combination, offer a useful alternative.

•**New Immunotherapies.** Though not new, Keyhole Limpet Hemocyanin, the oxygen-carrying molecule from a South Pacific “sea snail” is known to be effective in bladder cancer and is approved for treatment in several countries. I have had patients respond who have failed all my other options, but unfortunately it is not approved in the U.S. MCC is a promising immune stimulant conceived by Dr. Morales, who first gave BCG to bladder cancer patients. Made by Bioniche, it is the cell wall of a bacterium related to BCG that does not cause disease (*Mycobacterium Phlei*). It acts by both stimulating the immune system as well as directly killing bladder cancer cells and is being evaluated in clinical trials in the US and Canada. Like combination chemotherapy, combination immunotherapy using BCG with Interferon, interleukin 2 or other immune molecules is also very promising.

•**Gene Therapy.** I know of three gene or DNA based treatments that are promising for bladder cancer. Investigators at MD Anderson have developed a gene treatment related to interferon production. In Israel, investigators have developed a DNA based treatment that targets H19, a molecule that can promote cancer progression. Clinical trials have demonstrated some success and further studies are planned. Another gene therapy trial underway in this country uses a virus that targets and kills cancer cells and also is thought to act as a vaccine. These exciting projects will take time to perfect and gain approval, but are promising for the future of bladder cancer treatment.

**Q. Many patients who have had their bladders removed find themselves with frequent urinary tract infections. Is there anything a patient can do to prevent these infections? Will cranberry juice or any type of vitamin help in keeping such infections at bay?**

We are learning that old wives can be very wise and cranberry juice does in fact have some antibacterial activity. It is important for patients with recurrent infection to take in an adequate amount of liquid (to wash out bacteria) and to avoid urine retention. With the ileal loop diversion, contamination with bacteria is expected, but with an open, low pressure system serious infection is generally avoided. The stoma can scar and become tight, restricting the flow of urine. This narrowing can often be avoided by simply dilating the stoma with a finger periodically. Those with neobladders need to try to keep residual urine to a minimum. "Double voiding" to get the last bit of urine out, or taking extra time to be sure the catheter drains all of the urine in an Indiana pouch, can reduce the number of infections. Sometimes it is necessary to take suppressive antibiotics. Alternatively, some patients do best when they have antibiotic on hand to take at the first sign of infection. We have not, to my knowledge, demonstrated that vitamins can reduce urine infections, but vitamin C has been used to acidify the urine and make it less hospitable to some bacteria.

### Volunteer Corner



*Bettina Toner is a member of the newly created Volunteer Leadership Team. We thank her for sharing her story.*

I've been a runner for many years and along with the exhilaration and rewards of running come sundry aches and pains. Around age 34, I noticed that after taking Ibuprofen for knee pain, I'd sometimes notice blood in my urine. I vaguely remembered reading that some people have adverse reactions to taking Ibuprofen so I assumed that was the cause of the bleeding. I stopped taking Ibuprofen and the blood in my urine went away. I just figured I had developed an allergy or sensitivity to the Ibuprofen and thought nothing more of it.

A year or so later, my husband and I were expecting our first baby. Mid-way through my pregnancy, I began experiencing intermittent episodes of blood in my urine. My obstetrician determined that my pregnancy was fine but he was unable to determine the cause of the bleeding. He suggested that I see a urologist after our child was born.

As a teenager, I needed a Harrington Rod Spinal Fusion surgery to correct severe scoliosis. The metal rod that remains in my spine prevented me from having an epidural or spinal block for my daughter's delivery so she was delivered by Cesarean section while I was under general anesthesia. When I awoke after surgery, a good couple hours later than I had anticipated, I learned that during the delivery the doctors had encountered unexplained bleeding and then discovered that the source was one or more tumors in my bladder.

I returned to the hospital a month later for a tumor biopsy and was diagnosed with non-invasive, low-grade papillary carcinoma. This had been the source of the blood in my urine all along. Since the removal of the initial tumor, I have had several recurrences of similar low-grade papillary tumors. In December, 2006, I underwent a six-week course of BCG immunotherapy and I have not had any tumor recurrences since then.

When I look back now, I am amazed that I was so nonchalant about the blood in my urine. I understand now that it is a symptom that should always be discussed with a doctor. I am amazed that I was so naïve to ignore this symptom for over a year and a half before I was finally diagnosed, only coincidentally, during my daughter's birth.

I have always been a very healthy person and have never smoked so I was stunned when I was diagnosed with bladder cancer at age 36. Fortunately, my cancer is low-grade and I've found it to be manageable with regular follow-up visits to my urologist. The bladder cancer community is amazingly supportive and other bladder cancer survivors are really wonderful at sharing their stories and information. Resources such as BCAN have allowed me to connect with other survivors and to access reliable information about bladder cancer, both of which make the whole experience a lot less overwhelming.

## It's Complementary



Naturopathic medicine, or Naturopathy, is a distinct healthcare profession that combines natural, non-toxic therapies with current advances in health and medicine. It uses a wide range of approaches such as nutrition, herbs, manipulation of the body, exercise, stress reduction and acupuncture. A cancer patient might consider using naturopathic medicine as a complementary therapy in conjunction with his or her regular

conventional treatments, primarily for symptom relief.

According to The American Cancer Society, naturopathic treatments can be helpful in treating minor illnesses but should not be thought of as a curative treatment for serious illnesses such as cancer. However, the Society says that while the emphasis in naturopathic medicine is to uncover and treat the cause of disease, as opposed to merely treating symptoms, many of the individual treatment modalities are thought to help relieve some symptoms of disease and side effects of treatment cancer patients might experience.

The practice of naturopathy is based on six key principles:

- Promote the healing power of nature.** Naturopathic physicians act to identify and remove obstacles to healing and recovery and to facilitate and augment an inherent self-healing process.

- First do no harm.** Naturopathic practitioners choose therapies with the intent to keep harmful side effects to a minimum and not suppress symptoms.

- Treat the whole person.** Practitioners believe a person's health is affected by many factors including physical, mental, emotional, genetic, environmental and social and consider all of them when developing a treatment plan.

- Treat the cause.** Practitioners seek to identify and treat the causes of a disease or condition rather than simply suppress symptoms.

- Prevention is the best cure.** Practitioners teach ways of living they consider to be most healthy.

- The physician is a teacher.** Practitioners consider it important to educate their patients about taking responsibility for his or her own health.

According to the National Center for Complementary and Alternative Medicine (NCCAM) naturopathy appears to be a generally safe health care approach, especially if it is used as complementary (rather than alternative) medicine. However, there are several qualifying points to consider:

1. Naturopathy is not a complete substitute for conventional medical care.
2. Some therapies used in naturopathy have the potential to be harmful if not used properly or under the direction of a trained

practitioner. For example, herbs can cause side effects on their own and can interact with prescription or over-the-counter medicines.

3. Restrictive or other unconventional diets can be unsafe for some people.

4. The education and training of practitioners can vary widely.

*NCCAM provides this advice if you are considering integrating naturopathy into your care plan:*

**Tell your health care providers about any complementary and alternative practices you use.** Naturopathic physicians are trained to know that herbs and some dietary supplements can potentially interact with drugs and to avoid those combinations. Therefore, you need to tell them about all drugs (whether prescription or over-the-counter) and supplements you are taking.

**Talk to the naturopathic practitioner about his or her education and training (including any licensing or certifications they may have); any special medical conditions you have and whether the practitioner has any specialized training or experience in them; and costs and whether the services are covered by your medical insurance plan.**

**For more information about naturopathy, talk to your doctor and check these web sites:**

NCCAM at [www.nccam.nih.gov/health/homeopathy](http://www.nccam.nih.gov/health/homeopathy)

The American Cancer Society at [www.cancer.org](http://www.cancer.org) and type Naturopathic Medicine into the Search box

The Alternative Medicine Foundation  
[www.amfoundation.org](http://www.amfoundation.org).