

# Outlook

## **President's Message – Winter 2008**

Welcome to the new year and our new look! We've redesigned the format of our newsletter to make it easier for you to read and to share with others. Our new look also extends to our website and we hope you've also had a chance to check the new [www.bcan.org](http://www.bcan.org). We've added more information and new features, including our online community. Many have already joined this new community, sharing their experiences and making connections with others who are living with bladder cancer.

We continue to get tremendously positive responses to our educational offerings. Last November we saw a great turnout for our Webinar programs, offered in conjunction with the American Urological Association Foundation. In December we co-sponsored with Vital Options International a live radio program, and listeners rang the phones off the hook and sent a flurry of email questions. We are especially grateful to the medical experts for these programs who shared their wisdom and experience with the BCAN community: Dr. Mark Soloway, Dr. Mark Gonzalogo, Dr. Cheryl Lee, Dr. Steven Wong, and Josephine Silvestre, RN.

Please mark your calendars for our upcoming educational programs. Join us on **February 20 from 1:30-2:30 p.m. Eastern Standard Time**, as we partner again with *CancerCare* to present a **"Medical Update on Bladder Cancer,"** a free telephone educational workshop. Our panel of experts — Dr. Gary Steinberg, University of Chicago, Dr. Robert Dreicer, Cleveland Clinic, Dr. Matthew Milowsky, Memorial Sloan-Kettering Cancer Center, and Keith Lyons, CancerCare — will address a variety of issues in bladder cancer. The program is free, but registration is required. You can find registration information on our website.

On **March 29**, we will continue our program of regional patient forums. **"Understanding Bladder Cancer,"** an educational program directed at patients, family members and caregivers, will be held in Dallas at the campus of UT Southwestern. We are honored to have Dr. Arthur Sagalowsky, Professor and Chief of Urological Oncology at UT Southwestern, serving as our faculty chair. Details on this program and registration information will be posted on the BCAN website shortly.

We are pleased to welcome four new physicians to our Scientific Advisory Board: Dr. Sam Chang and Dr. Michael Cookson of Vanderbilt University, Dr. David Smith of University of Michigan, and Dr. Steven Wong of UCLA. We greatly appreciate the support we receive from bladder cancer experts throughout the United States and Canada.

As we enter our third year, we are grateful for our volunteers who give of their time, and for our growing family of donors whose generosity and support are essential to our continued growth and development. Together, we are making a difference.

Warmest wishes to you and your loved one for a new year filled with hope, good health and joy.

*Diane Zipursky Quale*  
*BCAN President*

## On Trial

We thank Dr. Matthew Galsky, principal investigator and a medical oncologist at the Comprehensive Cancer Centers of Nevada for providing this description of **“A Phase II Randomized Discontinuation Study of Lapatinib Administered Orally to Patients with Her-2 Positive Ovarian, Gastric/Esophageal Adenocarcinoma, Uterine Serous Papillary, or Bladder Cancer.”**

The US Oncology Research Network is currently recruiting patients with advanced bladder/urothelial carcinoma who have progressed despite prior chemotherapy for a phase 2 study of lapatinib, an oral drug which inhibits two proteins (EGFR and HER-2) that may play a key role in the growth and spread of urothelial cancers. This trial employs a novel design in which patients with urothelial cancer (and other solid tumors) have their prior biopsy or surgical specimens sent to a central lab to determine if the Her-2 protein is over-expressed. If the protein is over-expressed, then patients are offered enrollment on the clinical trial. This design attempts to select patients who are most likely to benefit from the treatment with the hopes of advancing “personalized” medicine.

In order to be eligible for this study, patients must have metastatic urothelial carcinoma that has progressed despite prior chemotherapy and must have adequate organ function. A signed consent form is required before participation in the study is allowed.

This study is being offered at several sites throughout the United States. For more information about this trial, contact Dr. Galsky at 702-952-3400 or [matthew.galsky@usoncology.com](mailto:matthew.galsky@usoncology.com).

## Ask the Doctor

Our questions for this issue of *Outlook* were answered by Dr. Arthur Sagalowsky, Professor and Chief of Urologic Oncology at UT Southwestern Medical Center in Dallas, TX. We sincerely appreciate his sharing his opinions and impressions with us.

### **Q: Is it safe to have sexual intercourse while undergoing BCG treatments?**

**A:** This is an excellent and very practical question about which there is embarrassingly little information. When introducing BCG, the catheter must be introduced without injuring or damaging the urethra, and recent biopsy sites must have healed to minimize the risk of infecting the patient with live BCG. Despite these precautions, some patients develop fever, rare systemic infection, and a small percentage of men may develop inflammatory conditions in their prostate or scrotum. In theory, men could shed BCG organisms in the urine, and possibly in the semen, in the first days after treatment. A barrier method such as a condom would confer protection against possible transfer of BCG to the sexual partner. However, I am not aware of any data that quantifies the presence of BCG in the urethra or the ejaculate after treatment. Nor have I ever heard of a case of the sexual partner becoming infected with BCG. Neither have several other bladder cancer experts to whom I posed the question. Clearly, we could all use better information on this point. Practically, I believe the risk, if any, must be small.

### **Q: What type of follow-up is recommended for patients following cystectomy?**

**A:** The data on this topic is limited and individual practice patterns are somewhat arbitrary. In my own practice, I believe the follow-up needs to take into account two equally important issues: possible tumor recurrence (metastases from original bladder tumor; new onset upper tract urothelial tumor); and monitoring of urinary tract kidney function. In addition, every cystectomy patient has some type of urinary diversion and is at increased risk for urinary infection, stones and ureteral obstruction from fibrosis or tumor. I see every postop cystectomy patient every 3 months during the first year and obtain:

- CBC, lytes, creatinine
- Chest X-Ray
- Abdomen/pelvic CT
- Urinalysis
- Liver function tests every 6 mos

During years 2 and 3 following cystectomy, the frequency of the above follow-up regimen remains:

- Every 3 months for patients who were stage T2,T3,T,4 or any T,node positive
- Every 6 months for patients who were stage To,T1, node negative

After year 3 I follow patients annually. The frequency of long term follow-up imaging recently has been a subject of controversy. While statistics indicate that recurrence after 3 years is unlikely, and that many patients with metastases present with symptoms, my 30-year bladder cancer practice has shown that patients are not statistics, and that unusual recurrences can arise at any time. In addition, the increasing number of patients with neobladders require other long term follow-up concerns arising from the need to maintain adequate voiding and possible metabolic consequences of continent urinary diversion. In short, I believe every patient who undergoes cystectomy and urinary diversion for bladder cancer requires and deserves lifelong annual urologic follow-up.

### **Volunteer Corner**

Like many of us, Brenda Neff (pictured above with her son) wanted to learn as much as possible about treatment options following her diagnosis of bladder cancer in 2002. And like many of us, she was very surprised to see that there was so little information available. For that reason, when she discovered BCAN, she decided to volunteer to help raise bladder cancer awareness in the hopes that more treatment options and hopefully a cure will one day be available.

Brenda started making jewelry when her mother was diagnosed with a very aggressive malignant brain tumor. Her first pieces were brain cancer awareness bracelets for herself and her two sisters. After her mother's death, she took some of her mother's necklaces and made them into bracelets so that she and her sisters would each have a special keepsake. Brenda found this jewelry-making very therapeutic, and after her own diagnosis, she decided to continue making jewelry, this time to benefit those dealing with bladder cancer.

Brenda's hand-made bracelets and key chains are now available from BCAN's [online store](#). All of the proceeds from the sale of these bracelets go to BCAN. We are very grateful to Brenda for using her talents to benefit BCAN.

### **It's Complementary**

Cancer patients utilize many types of complementary and alternative medicine (CAM) to help deal with their disease. That usage is now formally recognized by three federal agencies with the appointment of the first recipient of a new fellowship in medical oncology and CAM.

Scott Miller, M.D., of Iowa, is the first recipient of the new fellowship, jointly sponsored by the National Center for Complementary and Alternative Medicine (NCCAM), the National Cancer Institute (NCI), the NIH Clinical Center and the U.S. Food and Drug Administration (FDA). The three-year fellowship is designed to help new researchers gain expertise in CAM and cancer research, policy and regulatory affairs and clinical investigation.

"This fellowship provides physicians the opportunity to study CAM approaches in oncology," explained Patrick Mansky, M.D., director of NCCAM's Complementary and Integrative Medicine Consult Service at the NIH Clinical Center. "Dr. Miller brings an excellent degree of training and experience to this position." Dr. Miller's training included experience at a clinic that focused on cancer patients and CAM. According to Dr. Miller, a major challenge in patient care came from "unsafe duplication. Some clinic patients were using multiple products, up to 15 or 20 at once," he said. "Also, some preparations such as 'tonics' have multiple ingredients. I recall one patient who was taking a group of combination products; five contained selenium that, when added together, exceeded the recommended levels."

In order to avoid such situations, Dr. Miller said the clinicians at the clinic reviewed all of a patient's products, attempted to produce a rational strategy, if possible, and tried to avoid such duplications. Another challenge they faced was the fact that some herbs, such as St. John's Wort, can interfere with chemotherapy.

Among his responsibilities during his fellowship, Dr. Miller will learn about the use of CAM in cancer pain, symptom management and rehabilitation; learn about clinical trials methodology and design and carry out

an original research project; learn about regulatory issues pertinent to the use of CAM therapies, especially botanicals, through a rotation at the FDA; and perform patient evaluations and patient care as part of a team.

**Upcoming Events**

February 20: **Educational Workshop (telephone)**

*“Medical Update on Bladder Cancer”*

1:30 pm - 2:30 pm (est)

March 29: **BCAN Patient Forum**

*“Understanding Bladder Cancer”*

UT Southwestern Medical Center

Dallas, TX