



Winter 2010

President's Message

July 17, 2010 is Bladder Cancer Awareness Day

BCAN is organizing the first annual Bladder Cancer Awareness Day to be held on Saturday, July 17, 2010. We are working with dozens of local volunteers who are planning events around the country to raise awareness, including picnics, walk-a-thons, candle lighting ceremonies, and more. These events will hopefully receive local and national media coverage. [Visit our Volunteer Corner](#) for more information on this effort. To volunteer to help with an event or work with local media, please e-mail Janet McIver, BCAN's Information and Outreach Coordinator, at 888-901-BCAN (2226) or volunteer@bcan.org.

BCAN Award for Bladder Cancer Research

BCAN is pleased to announce that we are now accepting applications for the BCAN Award for Bladder Cancer Research. This \$25,000 grant will cover direct costs associated with a one year bladder cancer-specific research proposal. The purpose of this grant is to advance research that will increase the understanding of bladder cancer risk, biology, prevention, and treatment while encouraging young investigators to pursue a career in bladder cancer research.

The selection committee is eager to review all qualified applications, and we encourage you to distribute this grant information to any young researchers interested in investigating bladder cancer. The grant instructions and application can be downloaded from the BCAN website at www.bcan.org/medical/research-award/. The application is due April 26, 2010.

2010 Bladder Cancer Think Tank Meeting

The Bladder Cancer Think Tank met for the first time in the summer of 2006 with more than 30 participants. Since then, the Think Tank has grown tremendously while encouraging valuable collaboration among bladder cancer researchers and physicians. This August, BCAN will host approximately 100 leading bladder cancer physicians, researchers, advocates and survivors for the Fifth Annual Think Tank meeting in Traverse City, Michigan.

Working groups from the 2009 Think Tank have made incredible progress throughout the year on projects like developing a Bladder Cancer Survivorship Toolkit to provide critical information for bladder cancer patients, gathering information from across the country about treatment patterns, and creating a Bladder Cancer Research Network. Because of the success these groups have had, they will form the basis for the 2010 Think Tank program. We look forward to continuing to work with the meeting participants to improve the understanding and treatment of bladder cancer.

Scientific Advisory Board Additions

BCAN is pleased to welcome several new members to our Scientific Advisory Board:

- [Dr. Jessie Au](#), Distinguished University Professor at Ohio State University
- [Dr. Scott Gilbert](#), Assistant Professor and Medical Director of the Urology Quality and Safety Program at the University of Florida
- [Dr. Mark Gonzalgo](#), Associate Professor of Urology and Director of Robotic-Assisted Urologic Cancer Surgery at Stanford University. We especially appreciate Dr. Gonzalgo's participation in this issue's [Ask the Doctor column](#).
- [Dr. Yair Lotan](#), Associate Professor of Urology at UT Southwestern
- [Dr. Matthew Milowsky](#), Department of Genitourinary Oncology at Memorial Sloan Kettering Cancer Center
- [Dr. Raj Pruthi](#), Associate Professor of Surgery/Urology and Director of Urologic Oncology at the University of North Carolina at Chapel Hill
- [Dr. Jonathan Rosenberg](#), Assistant Professor of Medicine and Medical Oncologist at Harvard Medical School

New Staff Member

BCAN welcomes Grace Schroer as our new Marketing and Development Coordinator. More information about BCAN's staff is available [on our website](#).

Thank you all for your continuing support. With your help, BCAN is looking forward to another great year.

Diane Zipursky Quale
BCAN President

On Trial

In this issue of “On Trial” we are providing information on one clinical trial and one survey research project on bladder cancer survivorship.

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Phase 2 Study – Neoadjuvant Chemotherapy with Dose-Dense MVAC in Muscle-Invasive Urothelial/Bladder Cancer.

Dana-Farber Cancer Institute is enrolling patients into a phase 2 neoadjuvant study of dose-intensified chemotherapy with MVAC (dose-dense MVAC) and growth factor support in patients with muscle-invasive bladder cancer. Patients with clinical T2-T4a and N0-N1 are eligible provided they have good performance status and they are eligible for cisplatin-based chemotherapy. The dose-dense regimen will be given for 4 cycles followed by radical cystectomy and lymph node dissection. This regimen has been tested in the advanced/metastatic setting and was found to be better tolerated than the classic MVAC (less mucositis, neutropenia and infection) with higher rate of complete responders.

Our goal is to reach higher complete response in the tumor specimen than with classic chemotherapies such as MVAC or gemcitabine+Cisplatin, with the goal of achieving higher cure rates. The study will be collecting patients’ serum and tumor specimens’ in order to identify biomarkers of response and improved outcome with this regimen.

The study is set to open also at University of Pittsburgh, Pittsburgh, PA and Lahey Clinic, Burlington, MA

Overall PI [Primary Investigator] is Toni K. Choueiri, MD, genitourinary oncologist at Dana-Farber Cancer Institute and Harvard Medical School, email: Toni_Choueiri@dfci.harvard.edu

The purpose of this research study is to test the effectiveness of neoadjuvant chemotherapy (dose-dense MVAC) in combination with pegfilgrastim followed by radical surgery in patients with muscle-invasive urothelial carcinoma. For full details, [see the study listing at ClinicalTrials.gov](#).

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Researchers Recruiting Men and Women Diagnosed with Bladder Cancer within the Last Four Years for a Telephone Survey

Have you been diagnosed with bladder cancer?

Would you help us with a survey about your experiences with this type of cancer?

Baylor College of Medicine and the Michael E. DeBakey VA Medical Center are conducting a research program trying to understand how cancer affects the lives of men and women. The goal is to create a new patient education and counseling program for bladder cancer patients, so we need to understand your concerns.

Participation in the research project will not cost you anything and does not affect your healthcare.

The Project

People who take part in the project can expect

- A short phone call to make sure you are eligible to be in the study
- A phone-based survey that will last 45 to 60 minutes.
- The survey will include questions about when you were diagnosed, how you feel about having cancer, and how having cancer has affected your life.
- Participants will be compensated \$25 upon completion.

Eligibility

To be eligible for the study, you must be

- Diagnosed with bladder cancer within the last 4 years
- Able to speak English
- Able to receive project information through the mail and complete a survey by phone.

All information is **CONFIDENTIAL**.

This study is funded by the Scott Department of Urology at Baylor College of Medicine and is not associated with any business or commercial organization.

For more information, contact the **Bladder Cancer Patient Education Program at 1-877-794-7852 or CancerOutcomes@bcm.edu**.

Ask the Doctor

Dr. Mark Gonzalgo, Associate Professor of Urology and Director of Robotic-Assisted Urologic Cancer Surgery at Stanford University, shares his expertise regarding robotic cystectomy.

Q: I understand that a robotic cystectomy procedure is now available. What are the advantages/disadvantages of this procedure vs. open cystectomy? Is robotic cystectomy the preferred option for all patients undergoing bladder removal?

A: Standard surgical treatment for aggressive bladder cancer is radical cystectomy with an extensive lymph node dissection (removal of nearby lymph nodes). Traditionally, the surgery is performed through an incision in the abdomen just below the umbilicus (belly button). Hospitalization is generally between 5 and 10 days, and up to 6 weeks are needed for complete recovery. Over the past few years, both laparoscopic and robotic-assisted radical cystectomy have been developed for treatment of bladder cancer. These types of procedures are now being routinely performed at highly specialized centers. The principles of surgery remain the same, but the procedure is performed through smaller incisions using laparoscopic instruments. The use of minimally-invasive laparoscopic techniques in surgery is associated with faster recovery times, less pain, and less blood loss. Robotic-assisted laparoscopic surgery allows surgeons to perform certain techniques with less difficulty associated with traditional laparoscopic surgery. Robotic surgery has already revolutionized the treatment of prostate cancer and has surpassed the open procedure in terms of the number of radical prostatectomies performed annually in the United States. Robotic cystectomy represents one of the newest areas of clinical application for minimally-invasive surgical techniques in the field of urology.

Over the past few years, there have been an increasing number of centers that have adopted minimally-invasive approaches for radical cystectomy. However, the long-term effectiveness of this procedure is unknown. Currently, there are a few small, single-institution studies indicating that robotic cystectomy provides effective cancer control with decreased blood loss, transfusion rates, and length of hospital stay. Overall complication rates with robotic cystectomy have been reported to be similar to the traditional open procedure. There has been at least one randomized trial directly comparing robotic cystectomy to open radical cystectomy. One potential disadvantage of minimally-invasive techniques for treatment of bladder cancer is related to the extent of the lymph node dissection. Although there is still some controversy among urologists as to exactly how extensive of a pelvic lymph node dissection should be performed, there is no debate that one *should* be performed during radical cystectomy. In a recent study, however, robotic cystectomy was found not to be inferior to open cystectomy when comparing the number of lymph nodes removed during surgery. More studies and long term follow up are needed in order to better understand the role of laparoscopic and robotic-assisted techniques in bladder cancer surgery

Robotic surgery is not necessarily the preferred option for all patients undergoing bladder removal, but this procedure gives patients another surgical option that was previously not available. Regardless of whether a surgeon is using the robot or performing an open surgery, the goal remains the same: to achieve cancer cure with the lowest impact on a patient's quality of life. In general, most patients who are considering traditional open cystectomy for bladder cancer will also be suitable candidates for robotic cystectomy. The decision to choose robotic cystectomy for treatment of bladder cancer is a personal choice and should be made with the help of a urologic oncologist with expertise in both open and minimally-invasive surgical techniques.

Volunteer Corner

Bladder Cancer Awareness Day, July 17, 2010.

Volunteers around the US are already planning a dozen local or regional events to raise awareness about bladder cancer on (or close to) **July 17, 2010**. Additionally, **CBS's Bob Schieffer**, who is a bladder cancer survivor and long time steadfast BCAN supporter, has kindly volunteered to be a national spokesperson for the effort.

Many of the events are low key activities. Among other things, volunteers are organizing picnics and candle lighting ceremonies, participating in athletic events while wearing BCAN t-shirts, and providing educational materials at a local fairs and festivals.

Our Volunteer Leadership Team of five experienced, committed volunteers (Nancy, Dan, Veronica, Lynda, & George – known on our online community as balihigh, JerseyGuy, VTom, Ish, & Shiz) is now meeting regularly to finalize details of the resources we will provide local volunteer organizers to help them organize and publicize their events. Dan and Nancy organized the North Carolina Bladder Cancer Picnic last July, which is the inspiration behind holding events across the country for National Bladder Cancer Awareness Day. These volunteer leaders will act as mentors to local organizers, so rest assured – if you want to do something on July 17 you will not be on your own. Help will be available!

We would love for an awareness event to be held in your community in July. If you are interested in helping organize something, or you know someone who would be interested, please get in touch with **Janet McIver** today by phone at **888-901-BCAN (2226)** or via e-mail at volunteer@bcan.org.

Featured Volunteers – Randy Van Dusen and Jackie Nalls

BCAN Volunteer and police officer **Randy Van Dusen** continues to put his energy to good use to raise awareness about bladder cancer and BCAN. Having run in the California International Marathon in December, Randy is now training for the American River 50 Mile Endurance Run which takes place in April. Randy also plans to do an event on Bladder Cancer Awareness Day!

And after sharing her inspirational story on our website, **Jackie Nalls** continued to help BCAN by sending a "Write for the Cure" campaign to thirty eight family members and friends. This raised over \$1,000 for BCAN! Check out our new website section, [Volunteer Corner](#), to learn more about how you can [create your own "Write for the Cure" campaign](#), and read more about [Randy's story](#) and [Jackie's experience](#).

Other Upcoming Volunteer Opportunities

The American Association for Cancer Research (AACR): BCAN will be present at the annual AACR meeting in Washington DC from April 16 to 21. This is a major event which attracts over 11,000 medical and scientific cancer researchers. BCAN volunteers, Mary Ann, Bob, Stan, Trish, and Ev have offered to help staff BCAN's exhibit booth. If you live in the DC area and could help, please call 301-215-9099 or email volunteer@bcan.org)

BCAN Patient Forum: The next of our biannual patient forums will take place on May 15th at the University of North Carolina at Chapel Hill. BCAN needs volunteers to help with the registration desk at this free event. If you are attending and could help that morning, please call 888-901-2226 or email volunteer@bcan.org.

American Society of Clinical Oncologists (ASCO) Annual Meeting: This is another big event in the oncology calendar. ASCO will take place in Chicago from June 4 to 8th. BCAN volunteers Randy, Janet, Anna and Connie have already offered to help at the BCAN exhibit. If you live in the Chicago area and think you could help at the BCAN booth, please call 888-901-2226 or email volunteer@bcan.org.

Bladder Cancer Advocacy

In the last few months, several bladder cancer survivors have volunteered to represent the bladder cancer community on a national level. We want to thank them all for their time and commitment to the cause!

Rick Bangs – As the Bladder Cancer Patient Advocate for the Southwest Oncology Group, Rick meets regularly with oncologists and urological oncologists who are running large bladder cancer clinical trials. He currently is working to improve patient participation in bladder cancer clinical trials and giving feedback from a patient perspective on trials being considered.

Randy Layne – Randy was nominated by BCAN to be the bladder cancer patient representative on the FDA’s Oncology Drug Advisory Committee for a public hearing on the contrast drug needed for fluorescent/blue light cystoscopy. (The drug is known as Hexvix in Europe.) As a patient representative, Randy became a temporary voting member of the committee – which included oncologists, urologists, and biostatisticians – that recommended the FDA approve the intervesical use of this contrast solution for enhanced cystoscopic diagnostic imaging.

Robert Lipman – Bob testified at the FDA public hearing on Hexvix, offering his opinion of the importance and necessity of developing new, scientifically-verified diagnostic tests for bladder cancer.

Michael Jones – Michael, a retired pathologist, was nominated by BCAN to help the Department of Defense evaluate research proposals submitted to their **Peer Reviewed Cancer Research Program (PRCRP)**. Of the \$16 million appropriated by Congress for this program in fiscal year 2009, \$8 million was for grants for genetic cancer research (including bladder cancer research) that “related to exposures unique to the military.” As a consumer reviewer, Michael joined prominent scientists as a full voting member at meetings to determine how these research funds will be spent.

It's Complementary

We are learning now that what you eat—and what you don't eat—can have a powerful effect on your health, including your risk of cancer. Without knowing it, you may be eating many foods that fuel cancer, while neglecting the powerful foods and nutrients that can protect you. Changes in your diet, along with other lifestyle modifications, might help you minimize your risk of disease or possibly slow or stop cancer from developing. There are many books and on-line articles written about healthy eating and its relationship to cancer. We encourage you to explore them to find the dietary and lifestyle changes that are right for you. In the meantime, here are some suggestions from a variety of sources:

The American Institute for Cancer Research (AICR) says to:

- Eat more of a variety of vegetables, fruits, whole grains and legumes such as beans. At least 2/3 of your plate should be filled with vegetables, fruits, whole grains and beans.
- Limit consumption of red meats (such as beef, pork and lamb) and avoid processed meats
- Limit consumption of salty foods and foods processed with salt (sodium)
- Avoid sugary drinks. Limit consumption of energy-dense foods

You can find a wealth of specific information [at this site](#).

In his book *"Anticancer: A New Way of Life,"* Dr. David Servan-Schreiber, the noted neuroscientist, physician and author, (himself a cancer survivor) developed these additional tips:

- Spice it up: Add turmeric (with black pepper) when cooking. This yellow spice is the most powerful natural anti-inflammatory agent. Also, add Mediterranean herbs to your food: thyme, oregano, basil, rosemary, marjoram, mint, etc. They don't just add flavor, they can also help reduce the growth of cancer cells.
- Go fish: Eat fish two or three times a week and look for the varieties that contain less mercury and PCBs than other fish (sardines, mackerel and anchovies have less mercury and PCBs than bigger fish like tuna, swordfish and shark)
- Use only olive and canola oil in cooking and salad dressings. Don't use soybean, corn and sunflower oils...they are too rich in omega-6 fatty acids
- Instead of coffee or black tea, drink three cups of green tea per day.

And noted physician, author and talk-show host Dr. Mehmet Oz, director of the Cardiovascular Institute and Complementary Medicine Program at NY Presbyterian Hospital, has developed a shopping list of anti-cancer fighting foods to help to help you get started:

Blueberries, Garlic, Yogurt, Onions, Green Tea, Carrots, Rainbow chard, Sweet Potatoes, Tomatoes, Squash, Tempeh, Broccoli, Flaxseed, Beans, Quinoa, Curry

Remember though, no diet or lifestyle can guarantee you will live your life cancer-free. Nor should dietary changes take the place of your conventional medical care. However, adopting a lifestyle that includes healthy eating and exercise can help to keep your body and spirit as strong as it can be.