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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 are so happy to introduce the first issue of our newsletter, BCAN Outlook. Through this quarterly electronic publication we hope to keep you informed about BCAN activities and to let you know about the latest in clinical trials and what's new in research. We plan to include questions from patients and answers from physicians, survivor stories and lots more information that will help to keep you informed about bladder cancer and BCAN's efforts to increase awareness and the flow of research dollars for the diagnosis, treatment and cure of this disease.

It's been an active eight months since we established BCAN. We:

- Kicked-off our web site at www.bcan.org;
- Created a Scientific Advisory Board with more than 20 of the most prominent academic urologists, oncologists and radiation-oncologists representing major cancer centers around the country;
- Formed a Survivors Advocacy Board made up of nurses, nurse practitioners and research associates in the bladder cancer field. This new advisory group will provide advice and input on the BCAN website, our newsletter and the awareness/educational materials we produce.

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- Issued a press release in connection with Bladder Health Awareness Week that was picked up by a number of media outlets across the country. Dr. Mark Schoenberg, the Chairperson of Scientific Advisory Board, and I were interviewed for programs on Washington, DC radio stations during that week in November (You can listen to Dr. Schoenberg's interview on our website);

- Published BCAN's article, "Bladder Cancer: What Every Woman Needs to Know" in the fall 2005 edition of *Sexx Matters*, the newsletter of the Society for Women's Health Research. This same organization just published its book entitled *The Savvy Woman Patient: How and Why Sex Differences Impact Your Health*. Dr. Mark Schoenberg, Stephanie Shapiro (research intern) and I wrote the section on bladder cancer that is included in the book;

- Were introduced and warmly welcomed at the annual meeting of the Society for Urologic Oncology, which was held in December at the National Institutes of Health in Bethesda, MD;

- Hosted a booth at the 2006 NBC4 Health & Fitness Expo held at the Washington, D.C. Convention Center in January. BCAN distributed its new brochure as well as other educational information about bladder cancer. More than 200 people came by our booth for information.

We encourage you to share our newsletter with those you think would be interested and to add their names to our mailing list by signing onto our web site at www.bcan.org. If there is particular information you are interested in seeing or if you want to get involved in BCAN, please contact me through the web site as well.

Many thanks to Dale Heffler, BCAN volunteer, who has taken on the role as editor of this newsletter.

All of us at BCAN are so grateful for the support we've received from friends, family, members of the bladder cancer survivor community and the medical community. We are confident that with continued support we can make a huge difference in the fight against this disease.

We wish you and yours a healthy and happy 2006.

Diane Zipursky Quale

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On Trial



Each issue On Trial will include information about bladder cancer research being conducted at different medical institutions around the country. This quarter, we thank Rita Hench, BS, CCRC, Clinical Research Associate, Department of Urology, for providing us with a glimpse of the clinical trials being conducted at the University of Michigan.

• **A Study to Discover Protein Signatures of Patients with Transitional Cell Bladder Cancer.** The objective of this study is to find blood protein signatures that identify transitional cell bladder cancer. Study design is a retrospective, un-blinded, feasibility study that will compare patients with benign bladder disease, bladder cancer confined to the bladder and bladder cancer that has spread to other organs. In this study scientists will identify and distinguish bladder cancer from non-cancer by analyzing serum samples that contain the protein biomarkers for bladder cancer. Sponsor is Somalogic, Inc. Principal Investigator is Cheryl T. Lee, MD.

• **Experimental Clinical Studies of the Direct Intratumoral Administration of Autologous Dendritic Cells (ADC) for the Treatment of Muscle Invasive Bladder Cancer Prior to Cystectomy.** Objective is to determine whether autologous dendritic cell vaccine can be safely administered to patients with invasive bladder cancer and to determine the maximal tolerated dose of the vaccine. (Dendritic cells are immune cells obtained from one's own blood.) Secondary objective is to characterize the immune response to intratumoral autologous dendritic cell vaccination in bladder cancer patients. In this study scientists will monitor the research subjects for safety of the ADC vaccine as well as immune responses to the vaccine. Patients with invasive bladder cancer without metastasis (spread of cancer to other parts of the body) and are candidates for radical cystectomy (removal of the bladder) are eligible for this study. Sponsor is National Institute of Health and the American College of Surgeons. Principal Investigator is Cheryl T. Lee, MD.

• **Innovative Development of Novel Molecular Markers.** This study is to validate a biomarker to detect bladder cancer by examining genetic changes in DNA obtained through urine samples and blood samples; a non-invasive method of screening for bladder cancer. In this study scientists will compare genes found in the subjects blood to the genes found in the subjects urine to detect different patterns or occurrence.

The hope is that this will be a new way to detect or screen for bladder cancer. Sponsor and Principal Site is Johns Hopkins University and Health and Human Services, NIH. Site Principal Investigator is Cheryl T. Lee, MD.

• **Characterization of Neoadjuvant Paclitaxel, Carboplatin, and Gemcitabine Response in Locally Advanced Bladder Cancer.** Objective is to determine specific genetic factors that influence patient response to chemotherapy prior to cystectomy. In this study scientists will try to develop a classification rule for patient response to chemotherapy PCG (Paclitaxel, Carboplatin, and Gemcitabine) and predict response in future patients by analyzing tumor tissue genetics. Sponsor is NIH and University of Michigan O'Brien Center Grant. Principal Investigator is Cheryl T. Lee, MD.

• **Development and Validation of a Bladder Cancer Health Related Quality of Life Instrument.** Objective is to develop a clinical instrument to measure quality of life in bladder cancer patients. In this study researchers will give a questionnaire to patients after they have undergone bladder cancer surgery to determine their quality of life post-surgery. Sponsor is University of Michigan Department of Urology. Principal Investigator is David P. Wood, MD

For more information about any of these studies contact Rita Hench at rhench@med.umich.edu.

Ask the Doctor



Always wanted to know something about bladder cancer but were afraid to ask? Just “Ask The Doctor” by submitting your question to info@bcn.org.

Questions will be answered by physicians on our Scientific Advisory Board and will be posted in future newsletters. We thank Dr. Mark Schoenberg, Professor of Urology and Oncology and Director of Urologic Oncology at the James Buchanan Brady Urological Institute of Johns Hopkins Medical Institutions for the answers to these questions.

Q. I began bleeding about two or three weeks after I had a TURBT. Is this normal or should I contact my doctor immediately?

A. A small amount of bleeding is not uncommon for two – four weeks following a TURBT. About this time a small scab that has formed at the surgical site falls off, resulting in the bleeding you may see. This is not harmful unless so much

bleeding has occurred that it makes normal urination difficult or results in a significant drop in your blood count. If you have difficulty voiding or experience increasing fatigue with the bleeding it is best to let your doctor know immediately.

Q. I've noticed that physicians have different opinions about BCG maintenance. Can you explain the pros and cons?

A. Maintenance BCG involves the prolonged administration of BCG to patients with aggressive superficial bladder tumors who have had a good response to an initial six-week induction course of the medication.

Although the urologic literature contains many maintenance schedules, the schedule outlined in the 2001 publication by Dr. Donald Lamm and colleagues is probably the contemporary standard. According to Dr. Lamm's protocol, BCG is administered intermittently over 36 months after the initial six-week course. Periodic monitoring of the bladder occurs throughout the therapy.

The major difficulty with maintenance is bladder irritation. Only 20 percent of the patients in Dr. Lamm's study completed the entire course of treatment.

One important caveat: Aggressive superficial tumors can be successfully treated with BCG. However, not all tumors respond to the treatment, and unfortunately some tumors progress. Therefore, it is extremely important to have careful follow-up during maintenance therapy. I suggest a conversation with your physician at the outset of therapy about the appropriate course of action should maintenance therapy fail so that everyone has the same plan and expectations should disease recurrence or progression occur.

Volunteer Corner



Cynthia Kinsella, a BCAN director and bladder cancer survivor, is BCAN's volunteer Support Services Coordinator. She's been busy during the past few months organizing a variety of activities. Here's her report:

On November 27, we kicked off our BCAN support chatroom with our first on-line session. These support chatrooms are now held twice weekly—Sundays at 7:00 p.m. and Wednesdays at 8:00 p.m., Eastern Time. Each session lasts one hour and is monitored by me or another BCAN volunteer. The chats can be accessed through the home page of our website at

www.bcan.org. Anyone touched by bladder cancer is welcome.

In the coming months, BCAN will be focusing on developing bladder cancer support groups around the country. We have already started working with members of our Survivors Advocacy Board to establish support groups at their medical institutions. If you or someone you know would like to help start a support group in your community, please contact me at cdkinsella@bcan.org.

Because increased public awareness is one of BCAN's primary goals, we believe that participating in local health fairs is important. I am now working on scheduling for upcoming health fairs and need your help. I am looking for people who are willing to make calls in their local communities to find out when health fairs are scheduled (through hospitals, community centers, or other organizations). BCAN will provide all the necessary materials for distribution at a health fair. If you are interested in making calls in your community and/or helping to staff a booth at a local health fair, please contact me.

As a patient-based 501(c)(3) organization, BCAN need volunteer support. If at anytime you want more information on volunteer opportunities with BCAN or if you have any questions or suggestions about our programs, please feel free to contact me via email at cdkinsella@bcan.org.

It's Complementary



To take a more active role in our own healthcare, or simply to help ourselves feel better, many of us look to complementary therapies to use in combination with the treatments suggested by our physicians. Each quarter, It's Complementary will focus on one of these therapies.

Recent research from Northwestern Memorial Hospital found that art therapy can reduce a broad spectrum of symptoms related to pain and anxiety in cancer patients. In the study, published in the January 1, 2006 issue of the *Journal of Pain and Symptom Management*, cancer patients reported significant reductions in eight of nine symptoms measured by the Edmonton Symptom Assessment Scale after spending an

hour working on art projects of their choice. The symptoms included pain, tiredness, nausea, depression, anxiety, drowsiness, lack of appetite, well-being and shortness of breath. Of these, nausea was the only symptom that did not change as a result of the art therapy session.

According to an author of the study, Judith Paice, PhD, RN, director of the Cancer Pain Program at Northwestern Memorial Hospital, the study provides beginning evidence for the important role art therapy can play in reducing symptoms. “We wanted to see if the creative process involved in making art is healing and life-enhancing,” she says. “Art therapy provides a distraction that allows patients to focus on something positive instead of their health for a time and give patients something they can control.”