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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,

I am constantly amazed at how quickly time is passing. I hope that everyone is enjoying a wonderful summer with their friends, families and loved ones.

As always, it's been a very busy time for BCAN. We were at the American Urological Association Annual Meeting in Anaheim in May and had a very productive meeting with our Scientific Advisory Board. We are pleased to announce that Dr. Cheryl Lee, Assistant Professor of Urology, University of Michigan, will be serving as Chair of the SAB. We are indebted to Dr. Mark Schoenberg, past Chair of the SAB, whose dedication and support of BCAN was critical to BCAN's creation and to its development over the past two years. We would also like to welcome the new members of our SAB: Donna Hansel, MD, PhD, Assistant Professor, Department of Pathology and Laboratory Medicine, Cleveland Clinic; Yves Fradet, MD, FRCSC, Professor of Surgery, Universite Laval; Michael Jewett, MD, FRCSC, Professor of Surgery, Division of Urology, University of Toronto; J. Stephen Jones, MD, FACS, Vice Chairman, Glickman Urological and Kidney Institute, Cleveland Clinic.

While at the AUA Annual Meeting, BCAN partnered with Vital Options International and the AUA to present a live call-in radio show featuring Dr. Mark Schoenberg and Dr. Michael O'Donnell who addressed new developments in bladder cancer. Hundreds listened into the show and the doctors were

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able to answer many questions.

The month of June found BCAN in Chicago for the Annual Meeting of the American Society for Clinical Oncology. BCAN, along with many other patient organizations, participated in the Patient Advocacy Booth. Many thanks to BCAN volunteers Connie Meeks, Randy Layne and Pat Screeden for helping out at the booth. In addition, we are grateful for the scholarship we received from the ASCO Foundation to defray our costs to attend the Annual Meeting.

Save the Date: Speaking of Chicago, BCAN will be sponsoring its next patient forum, **“Understanding Bladder Cancer”** on **Saturday, October 13, at the University of Chicago**. Dr. Gary Steinberg, University of Chicago, is our faculty chair and the other members of our panel of experts are Dr. Cheryl Lee, University of Michigan; Dr. Marcus Quek, Loyola University Medical Center; Dr. Norm Smith, Northwestern University; Dr. Walter Stadler, University of Chicago; Josephine Silvestre, RN, University of Chicago; and Janice Colwell, RN MS, CWOCN, University of Chicago. Check the website soon for more specific details and registration information.

Our anniversary celebration on June 24 was a great success. The sun was shining and the mosquitoes stayed away as Bob Schieffer and the Honky Tonk Confidential entertained guests in the Quale backyard. We raised \$40,000 from this event, which will be used to support BCAN's educational and outreach activities. Our warmest thanks go out to the BCAN supporters who contributed to this celebration.

As a public non-profit organization, BCAN relies on the generosity of our supporters to further our mission. In that regard, individual donors are vital to BCAN's ability to lead the way to awareness, early diagnosis, and ultimately, a cure for bladder cancer. In appreciation and recognition of those individuals who have donated \$1,000 or more in a calendar year, BCAN is creating the BCAN of Light Partners program. We are proud to have the following individuals as charter members of this new program and are ever grateful for their generosity.

BCAN of Light Partners 2005: Renee and Jim Bayes, Toni and Dwight Bush, Ursula and Ron Cuneo, Nancy and David Lesser, Andrew and Sally Quale Foundation, Diane and John Quale, Linda and Charles Sullivan, Catherine and Tim Thompson, Janet and Sydney Thompson, Jane and David Wilson, Charlotte and Morley Zipursky.

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

Dan Theodorescu, M.D., PhD
University of Virginia Health System

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BCAN of Light Partners 2006: Ashley Family Foundation, Ellen and Richard Bodorff, Toni and Dwight Bush, Richard W. Caudell, Tate Donovan, Eugene Lynch, Peter Mathes, Jill Neilson, Diane and John Quale, Thomas Queen, Susan Schaffer and Mike Rogan, Pat and Bob Schieffer, Patricia and Jim Screeden, Jan and Rich Scolio, E. Michael Scott, Rebecca and Jared Sher, Jane and David Wilson.

BCAN of Light Partners 2007: Ashley Family Foundation, Toni and Dwight Bush, Darby Foundation, Louise de la Fuente and Mace Rosenstein, Claude George, Carol and Peter Kaplan, Phyllis and Robert Newman, Andrew and Sally Quale Foundation, Diane and John Quale, Susan Schaffer and Mike Rogan, Pat and Bob Schieffer, Jan and Rich Scolio, Jane and David Wilson, Charlotte and Morley Zipursky.

In closing, I am happy to introduce you to BCAN's first, and for now, only employee—Christine Scott, BCAN's Director of Outreach and Operations. Christine's responsibilities are wide-ranging and she will be working with me on program development, website enhancement and community outreach. Christine can be reached at cascott@bcan.org.

Sincerely,
Diane Zipursky Quale
President

On Trial



We thank Dan Theodorescu, MD, PhD and Christopher Y. Thomas, MD, of the University of Virginia Health Systems and Cheryl Lee, MD, University of Michigan, for providing us with the following description of the promising development of COXEN as a predictor for personalized chemotherapy.

Intravenous chemotherapy is an important part of the treatment plan for bladder cancer patients with tumors that have grown into or through the muscle wall of the bladder or spread to lymph nodes or other organs. The origin of the cancer determines the type of chemotherapy that patients receive. However, even though all bladder cancers arise from the same organ, they can behave very differently. Just as some cancers are more aggressive than others, some are less likely to respond to chemotherapy than others. These differences probably relate to the genetic makeup of the cancer cells. Ideally, chemotherapy would only be administered to patients with a high likelihood of responding to the treatment, as measured by tumor shrinkage. Currently, doctors and scientists are unable to

distinguish patients who will respond favorably to chemotherapy from those who will never respond. In addition, while thousands of compounds are being synthesized by chemists, there are essentially no generally reliable ways to predict which of those compounds will be effective in patients. Cell and animal models have not been useful in this regard. Therefore, many useful compounds end up neglected while others are only found to fail after expensive and time consuming clinical trials.

This month, an approach called Co-eXpression Extrapolation or “COXEN” was published by investigators at the University of Virginia and the National Cancer Institute (NCI), www.coxen.org. This approach goes a long way toward addressing the two challenges mentioned above. Using simple in vitro cell based drug sensitivity assays and gene expression profiling, this technique will allow screening of large chemical libraries to come up with candidates that are very likely to be effective in any human cancer. Indeed these investigators have already done “proof of principle” screening of the 45,000 drugs in the NCI public library and have come up with novel drugs for bladder cancer, some of which have been evaluated in depth and confirmed as having superior activity in vitro and in vivo to current chemotherapeutic agents. In addition, COXEN offers the promise to select patients for Phase II and III clinical trials that are most likely to respond or to select the optimal single or combination chemotherapy regimen for patients that are not on trial, among FDA approved anticancer agents allowing for “personalized cancer treatment”.

Currently, a collaboration is developing between the University of Virginia, the University of Michigan and the Southwest Oncology Group (SWOG), one of the largest organizations in the country that organizes national clinical trials. This partnership will couple expertise in areas of basic science and clinical research by using patient tumor samples obtained from a recent SWOG-sponsored research study. The tumor response predictions of COXEN will be compared to actual responses seen in the trial thus strengthening the validity and usefulness of the COXEN tool. The relationship with SWOG is extremely important since findings from our upcoming study may be used in future SWOG trials, making bladder cancer studies available to patients across the country. Furthermore, for patients that have failed first line chemotherapy, a Phase II trial is being currently designed that uses COXEN to select the optimal second line chemotherapy regimen among FDA approved anticancer agents. Integration of novel agents into combinations using established agents is also being contemplated.



Many thanks to Dr. Cheryl Lee, Assistant Professor of Urology, University of Michigan, and Chair of BCAN's Scientific Advisory Board, for responding to our questions below. Remember, if you have something you'd like to know e-mail your questions to us at info@bcan.org.

Q. How often does an individual with recurrent low-grade papillary tumors develop more aggressive high grade tumors?

A. Low grade papillary tumors are commonly seen in bladder cancer patients. These tumors, also termed Ta tumors (Stage 0a), arise on the surface of the bladder mucosa (superficial bladder lining). These tumors can become more “aggressive” if they begin to penetrate the bladder wall (stage progression) or if the appearance of their cells change into a “high” grade (grade progression). Although low grade tumors recur in 50-70% of cases, they rarely progress in stage. In a Swedish study reported in 1999, 255 patients presenting with low grade Ta bladder tumors were followed over time. Only 2.4% of patients progressed to a higher stage tumor. Similarly, other studies demonstrate a low risk of grade progression, which is seen in

Q. There was a recent study released indicating that a protein, A1BG, is present in the urine of bladder cancer patients, and may be a possible biomarker for bladder cancer. Can you provide more explanation and detail on this study?

A. Scientists from the University of Florida, Gainesville and the University of Michigan have recently developed a technique to profile selected proteins in voided urine specimens. The research team identified and evaluated 186 proteins. One protein of interest, alpha-1- beta-glycoprotein (A1BG), was found in the urine of patients with bladder cancer, but not in urine obtained from individuals without cancer. The function of the A1BG protein, initially discovered in 1986, is currently unknown. The results of this study are very preliminary, but further testing of the A1BG protein could lead to the development of a novel biomarker of bladder cancer.

Although the results are interesting, they are based on urine samples from only 10 research subjects. So, larger studies are

needed to determine whether A1BG will be a clinically useful tool for patients.

The scientific article is published in the Journal of Proteome Research. Volume 6, pages 2631-2639, July 6, 2007. The title is, "Bladder Cancer Associated Glycoprotein Signatures Revealed by Urinary Proteomic Profiling." The study authors are Paweena Kreunin, Jia Zhao, Charles Rosser, Virginia Urquidi, David M. Lubman and Steve Goodison.

Volunteer Corner



This month, we are pleased to profile one of our energetic National Volunteer Board Members, Karen Godfrey from Estero, Florida. Like many women bladder cancer survivors, Karen was misdiagnosed for many years before learning she had invasive bladder cancer. She received a radical cystectomy in January 2004 and has been cancer-free since. Below, in her own words, Karen describes her journey to gain information and how she is helping BCAN raise awareness and funding for bladder cancer.

"In the fall of 2003, I was diagnosed with invasive bladder cancer. My search on the internet for help in understanding this cancer proved to be a daunting task. There was precious little out there to explain what treatments were available. I was so grateful when BCAN was launched a few years later...a welcome resource for bladder cancer survivors. It has been my pleasure to serve as a volunteer with BCAN to help bring about better awareness of this cancer among the general populace as well as the medical community.

I am currently participating in BCAN's 'Write for the Cure' campaign. I have been profoundly gratified to see the response to my letter. I have received generous donations, often times with personal notes of encouragement. Sending out these letters also gave me the opportunity to let friends and family know about my personal battle while at the same time, helping them learn about this relatively little known cancer and its symptoms. I am well on my way to reaching the goals I set for myself: helping BCAN to have a broader outreach as well as a firm financial basis to advocate for bladder cancer research and ultimately a cure. I encourage all of you to get involved in 'Write for the Cure'. Together we can make a difference."



There have been a number of modalities used over the years to promote or maintain the balance of energy fields in the body. One of these modalities, Reiki, is a Japanese technique for stress reduction and relaxation that is also said to promote healing.

Reiki practitioners claim that the therapy boosts the body's immune system, enhances the body's ability to heal itself and is beneficial for a wide range of problems. It is not fully known whether or not Reiki actually influences health or how it might do so as there has been little rigorous scientific research to support its effectiveness. However, the National Center for Complementary and Alternative Medicine is currently sponsoring studies to find out more about Reiki's effects, how it works and diseases and conditions for which it might prove helpful.

Reiki is administered by "laying on hands" and is based on the idea that an unseen life force energy flows through each of us and is what causes us to be alive. Reiki practitioners believe that if one's life force energy is low, we are more likely to get sick or feel stress. If it is high, we are more capable of being happy and healthier.

During a Reiki session, a person sits or lies comfortably, fully clothed. The practitioner places her hands on or slightly above the person's body, using 12 to 15 different hand positions, with the intent to transmit ki ("life force energy" pronounced kee). Some Reiki practitioners believe they are helped by "spirit guides" for proper flow of the energy.

Practitioners say a deep sense of relaxation following a Reiki session may have beneficial health-related effects, such as reducing pain, nausea and fatigue. Reiki appears to be generally safe, and serious side effects have not been reported.

People have sought Reiki treatment for a wide variety of health-related purposes including the effects of stress, chronic pain, recovery from surgery and anesthesia, side effects of chemo or radiation therapy, to improve immunity or for a general sense of well-being.

As with any complementary or alternative therapy, Reiki should be used in conjunction with traditional therapies and not alone. For more information, visit the National Center for

Complementary and Alternative Medicine web site at
www.nccam.nih.gov