



Winter 2009

President's Message

We are thrilled to welcome Claire Saxton as BCAN's first Executive Director. Claire has over fifteen years experience as a non-profit manager and fund development professional, including as Executive Director of the Breast Cancer Resource Center in Austin, Texas. Claire received her MBA from the University of Oregon. In conjunction with BCAN's Board of Directors, Claire is responsible for shaping and leading BCAN as we continue to expand. For more information about Claire, please visit our website, www.bcan.org.

Our next regional patient forum, "**Understanding Bladder Cancer**" will be on May 16, 2009, in Cleveland, Ohio, in partnership with the Cleveland Clinic. Drs. Stephen Jones and Donna Hansel (both members of BCAN's Scientific Advisory Board) are serving as our faculty chairs, and have designed an informative and interactive program with specialists from the Cleveland Clinic and Ohio State University. More information will be available on our website soon.

BCAN welcomes two new members to our Scientific Advisory Board: Dr. Neal Shore, Medical Director of the Carolina Urologic Research Center and Dr. Matthew Nielsen, Assistant Professor of Urologic Surgery at University of North Carolina at Chapel Hill. More information about each of these doctors can be found on our website, www.bcan.org.

Our outreach to the public continues to increase. The response to our new booklet, ***Bladder Cancer Basics for the Newly Diagnosed***, has been overwhelming, and we have already distributed more than 7500 booklets to survivors, cancer clinics and physicians offices. We are very grateful to GE Healthcare which provided the unrestricted educational grant to support the creation and publication of this valuable resource.

Our online community is growing everyday. We have more than 450 members who engage in daily interactive dialogue and provide support for each other. If you haven't already done so, please check out our online community and consider joining.

Warm thanks go out to the more than 225 supporters whose generosity made our year-end fundraising effort so successful. With the help of the Directors Matching Grants from David Pulver and myself, BCAN raised \$100,000 which will enable us to continue to expand our services to the survivor community and to increase our efforts to advance bladder cancer research. This response would be tremendous in normal times—in our current economic climate, it is extraordinary! Together, we are making a difference in the lives of those affected by bladder cancer.

We are all looking forward to a springtime filled with sunshine and good health.

Diane Zipursky Quale

On Trial

This issue, we are providing summaries of three new clinical trials. We thank Dr. Matthew Galsky, U.S. Oncology Research, and Dr. Guru Sonpavde, Baylor College of Medicine, for providing us with this information.

Phase II Trial of Gemcitabine, Cisplatin, and Sunitinib in Patients With Advanced/Metastatic Urothelial Carcinoma

This is a phase II trial of the combination of a standard chemotherapy regimen (gemcitabine plus cisplatin) given in combination with a novel “targeted” drug called sunitinib. Sunitinib seems to work in cancers by disrupting the formation of blood vessels that feed tumors. Sunitinib has shown promising activity when given alone to patients with advanced bladder cancer that has progressed despite chemotherapy. Based on laboratory models of bladder cancer, giving sunitinib with chemotherapy might enhance the effectiveness of chemotherapy. The current study will determine the effectiveness and safety of a treatment regimen of gemcitabine, cisplatin, and sunitinib. The chemotherapy is administered intravenously while sunitinib is administered orally.

This trial is for patients with advanced bladder cancer that have not received prior chemotherapy. The trial is open at sites throughout the United States. For further details and inquiries regarding the nearest location, please contact Mary Ann Rauch, GU Program Manager, US Oncology, 281-863-4681, mary.rauch@usoncology.com, or Dr. Galsky at matthewgalsky@usoncology.com.

Brief Neoadjuvant Dasatinib for Muscle-invasive Bladder Cancer Followed by Radical Cystectomy: a Hoosier Oncology Group (HOG) Consortium Trial

Novel agents with activity in the setting of bladder cancer are necessary. Dasatinib is a new orally administered agent that is FDA-approved for resistant chronic myeloid leukemia and is being investigated for several other malignancies. Dasatinib inhibits several proteins that promote tumor growth including SRC-kinase, which is commonly found in bladder cancer cells. Preclinical experiments in the laboratory have demonstrated activity against bladder cancer. A pilot clinical trial was designed to determine the safety and feasibility of treatment with dasatinib that will accrue 25 patients. Dasatinib 100 mg will be administered orally once daily for 4 weeks duration (+/- 1 week) prior to radical cystectomy for patients with muscle-invasive transitional cell carcinoma of the bladder ineligible for and/or willing to forgo neoadjuvant cisplatin-based combination chemotherapy. The study will also assess the pathologic and biologic response in tumor tissue associated with dasatinib treatment. Following cystectomy, investigators may offer other conventional chemotherapy agents if warranted. For more information, please contact the Hoosier Oncology Group at 317-921-2050 or Dr. Guru Sonpavde at guru.sonpavde@usoncology.com.

Combination Gemcitabine, Cisplatin and Sunitinib Malate for Muscle-invasive Locally Advanced Bladder Cancer Followed by Radical Cystectomy: a Hoosier Oncology Group (HOG) Consortium Trial

Neoadjuvant cisplatin-based combination chemotherapy is considered a standard for locally advanced bladder cancer before radical cystectomy. Conventional neoadjuvant systemic chemotherapy with GC (gemcitabine, cisplatin) induces complete pathologic responses (no pathologic evidence of cancer) in approximately 30% of patients. Achieving pathologic complete response correlates robustly with improved survival. Therefore, one way to develop new regimens may be to attempt to attain higher rates of pathologic complete responses. Sunitinib malate is a promising new oral agent that primarily inhibits angiogenesis and is FDA-approved for kidney cancer. Sunitinib has been combined with chemotherapy in other cancers; furthermore, it was active in a preclinical model of bladder cancer and enhanced the

activity of cisplatin chemotherapy. A phase II trial of 46 patients with locally advanced muscle-invasive bladder cancer was designed to evaluate the combination of GC and sunitinib, with the primary goal of determining the pathologic complete response rate, with a 50% rate being of interest. Patients will receive 4 cycles of therapy over 3 months followed by radical cystectomy. Accrual began in January 2009. For more information, please contact the Hoosier Oncology Group at 317-921-2050 or Dr. Guru Sonpavde at guru.sonpavde@usoncology.com

Ask the Doctor

Our questions for this issue of Outlook are answered by David Latini, Ph.D, Assistant Professor of Urology at Baylor College of Medicine. We sincerely appreciate Dr. Latini's sharing his expertise on cancer survivorship issues.

Q. You conduct research on health-related quality of life among cancer survivors. Based on your research, do you have any concrete tips for bladder cancer survivors to improve quality of life for themselves and their families? Are there issues that bladder cancer survivors should be asking their doctor to address that can improve their quality of life?

A. I think the best advice I can give survivors is to ask for help when they need it. That goes for everything from help with managing physical symptoms like incontinence or sexual dysfunction or the feelings that come up when they find out they have cancer or later as they live with the possibility of recurrence. Sometimes just admitting that you need help is very hard, particularly when the help you need is related to subjects that are hard to talk about like urination or sexual problems. Research from a national prostate cancer database showed that urologists sometimes aren't very good judges of quality of life in their patients. Your doctor and other health care providers may be able to help manage treatment-related side-effects and other concerns if you let them know what's troubling you.

Many large hospitals have incontinence centers that can help you manage urinary side-effects of your treatment. Your urologist and your primary care provider can help you manage sexual dysfunction after BCG or other treatment. Educate yourself with books like Dr. Leslie Schover's *Sexuality and Fertility After Cancer* (New York: Wiley; 1997). BCAN hosts an online support community on its website, www.bcan.org, specifically for bladder cancer survivors, caregivers and family members. In addition, the American Cancer Society hosts the Cancer Survivors' Network on their website (www.cancer.org). The Wellness Community (www.thewellnesscommunity.org) also has both in person and electronic resources for cancer survivors. These organizations have a wealth of information and opportunities for support where survivors can learn from the experiences of others who have struggled with the same problems.

Q. Because of bladder cancer's high recurrence rate, lifelong monitoring and testing is required of most bladder cancer survivors. Do you have any recommendations on how survivors can best cope with the constant anxiety of waiting for test results?

A. Anxiety from monitoring is a real problem, not just for bladder cancer survivors but for survivors of other cancers as well. And unfortunately, we sometimes don't do a good job of supporting survivors struggling with anxiety about the possibility of recurrence or progression. If you feel like you want to talk to someone about your fears, the American Psychosocial Oncology Society offers a toll-free helpline to locate a counselor in your area. You can dial 1-866-276-7443 (1-866-APOS-4-HELP) or you may send an e-mail to info@apos-society.org with "Helpline" in the subject field. Or talk with a minister or other religious leader.

One of the best ways to manage anxiety is to take your mind off what's bothering you. Volunteer with a group in your community to do something to help others. Spend time with your loved ones. Learn to meditate or do tai chi! Exercise or just take a walk with your spouse or partner.

Another good way of managing your fears is to learn the most you can about your cancer. What are the new treatments being developed? Attend BCAN conferences or webinars to keep up with new developments. Get involved with BCAN or local organizations fighting cancer.

Q. What future research projects are you considering that might help improve bladder cancer survivors' quality of life as they navigate their treatment path and their long-term survivorship?

A. Very little research has been done on quality of life in bladder cancer survivors. Most of the research that has been done has focused on muscle-invasive disease, even though about 80% of new diagnoses are in nonmuscle-invasive disease. It's also hard to advocate for more money and services for bladder cancer survivors until we do the basic research to document the quality of life concerns and distress that many people face. We've been enrolling survivors in a telephone survey and hope to use data from that study to encourage more research, particularly on survivorship.

We recently asked the National Cancer Institute to fund a project to modify an educational program we developed for prostate cancer survivors to make it appropriate for nonmuscle invasive bladder cancer survivors. We're hoping to create a symptom management program that will be tailored to the specific problems that survivors face. The program will be provided over the telephone and through the mail, with materials written at the 6th grade reading level. We particularly want to target survivors in rural areas and smaller cities, where people may not have access to large cancer centers. We also hope to develop patient decision aids to help people look at the pros and cons of different treatments or other important medical decisions, like the type of urinary diversion they select.

Volunteer Corner

Sometimes out of loss comes a commitment to make a difference. That is the case with one of our extraordinary volunteers, Mary Ann Aregood. Her participation in BCAN's medical outreach program is a tribute to her late husband Jack and a promise she made to him. Below is her story in her own words. In June, 2001 my husband Jack, retired after teaching for 31 years and we moved from New Jersey to the foothills of Virginia. Soon afterwards, Jack was diagnosed with bladder cancer.

After the initial shock, I tried to pull myself together and gather information about bladder cancer. Being a nurse, I was familiar with medical issues, but bladder cancer was foreign to me. A lot of phone calls were made and several consultations were done. Jack had his kidney removed at John Hopkins in May 2002. He eventually underwent BCG treatments and chemotherapy at UVA Medical Center. Jack was also involved in two clinical trials at The University of Indiana and Fox Chase.

Throughout Jack's illness, I spent a lot of time on the internet and came across the BCAN website. I called BCAN and was so happy to hear there was such an organization. Up till that point, I felt so alone and responsible in finding appropriate care.

On March 13, 2008 my beloved husband passed away. Before Jack died, I told him that I would do volunteer work for BCAN. My goal is to help others so that what happened to Jack may not have to happen to someone else. When I meet Jack in heaven, I want to be able to say to him, "Yes, we did it! There is a cure for bladder cancer!"

It's Complementary

Recent reports indicate that the relationship between bladder cancer and what you eat continues to be examined closely.

In our fall 2006 issue, *Outlook* focused on the phenomena of probiotics and noted that a report issued in 2005 by NCCAM and the American Society for Microbiology noted encouraging evidence of probiotic use to reduce recurrence of bladder cancer.

More recently, in a report published in the *American Journal of Clinical Nutrition* this past fall, Swedish scientists concluded a nine year study that examined 82,000 people and their yogurt consumption. Results showed that men who ate two servings of yogurt per day reduced their risk of developing bladder cancer by 36 percent; women by 45 percent. Other dairy products did not reveal such benefits. "Cultured milk products such as yogurt contain lactic acid bacteria, which have been shown to suppress bladder cancer in rats," the report by the Karolinski Institute in Stockholm said. "Our research suggests a high intake of yogurt in humans may reduce the risk."

In another study published in the December issue of *Cancer Prevention Research*, researchers suggest that selenium, a trace mineral found in grains, nuts and meats, may aid in the prevention of high-risk bladder cancer.

Researchers from Dartmouth Medical School compared selenium levels in 767 individuals diagnosed with bladder cancer to the levels of 1,109 individuals from the general population. Findings showed that women, moderate smokers and those with p53 positive cancers who had higher rates of selenium also had significant reductions in bladder cancer.

While other studies have shown a similar association between selenium and bladder cancer among women, this study is one of the first to show an association between selenium and p53 positive bladder cancer.

"Ultimately, if it is true that selenium can prevent a certain subset of individuals, like women, from developing bladder cancer, or prevent certain types of tumors such as those evolving through the p53 pathway from developing, it gives us clues about how the tumors could be prevented in the future," said Margaret Karagas, PhD, corresponding author of the study and professor of community and family medicine at the Norris Cotton Cancer Center at Dartmouth.

Dr. Karagas hopes to replicate these findings on a larger scale.

Yogurt? Selenium? If you are thinking about using either to complement your medical routine, talk with your doctor.

Upcoming Events

BCAN Patient Forum "**Understanding Bladder Cancer**"

May 16, 2009, Cleveland, Ohio

In partnership with the Cleveland Clinic, Drs. Stephen Jones and Donna Hansel (both members of BCAN's Scientific Advisory Board) are serving as our faculty chairs and have designed an informative and interactive program with specialists from the Cleveland Clinic and Ohio State University. More information will be available on our website soon.