

Outlook

President's Message - Summer 2008

As many of you know, my beloved husband, John Quale, died of bladder cancer on June 29. Surrounded by our family and closest friends, John passed away without pain at our home. John was initially diagnosed with bladder cancer in 2000, and our journey involved a variety of treatments, including immunotherapy, chemotherapy, chemo-radiation and radical cystectomy. Through it all, John lived his life one day at a time, appreciating the joy and love we found in each day together. John was a man of great optimism and strength, and never considered his cancer to be an insurmountable obstacle. As described by a member of BCAN's Scientific Advisory Board, "John was a man of great foresight, courage and compassion."

John and I created BCAN in 2005 because we were troubled by the lack of public attention given to bladder cancer, and the lack of advancements in treatment options. Our vision for the organization was to create a community to provide better information and resources for bladder cancer patients and their families to help empower them in dealing with their disease, and to encourage the medical research community to devote more time and resources to finding better treatments, and ultimately a cure, for bladder cancer. While John was very proud of what we have accomplished with BCAN in a short time, he understood that we have so much more to do.

I urge you to join me in honoring John's vision and courage by continuing to support BCAN's mission and programs. Help us spread awareness by telling your family, friends and colleagues about BCAN. Consider participating in our volunteer activities. We greatly appreciate your financial support and are establishing the John C. Quale Memorial Fund to ensure BCAN's continued operation and growth. We are extremely grateful for the contributions we have already received in John's name.

John was a remarkable man and is greatly missed.

Diane Zipursky Quale
BCAN President

Ask the Doctor

Our questions for this issue of Outlook were answered by Dr. Michael Cookson, Professor of Urologic Surgery at Vanderbilt University in Nashville, Tennessee. We sincerely appreciate his sharing his opinions and impressions with us.

Q. Many people delay having a radical cystectomy until it is far too late. Are there any guidelines for a person to use when considering when to have the surgery?

A. In patients with muscle invasive bladder cancer who are medically fit to undergo major surgery, radical cystectomy remains a gold standard treatment option offering unparalleled local cancer control and cure when the tumor is contained within the specimen. While the decision to proceed with cystectomy for muscle invasive disease is not controversial, there is debate as to the timing of the surgery. Specifically, there has been an increasing awareness of the fact that delay in the cystectomy may result in more advanced pathologic staging as compared to those who undergo surgery in a more timely fashion. Most importantly, a delay of more than 3 months from the time of diagnosis to cystectomy has in some studies resulted in a worse cancer-specific survival as compared to those who undergo cystectomy earlier.

It is important to note, however, the limitations of some of these studies, as they may not address the reasons for delay (e.g. additional cardiac or pulmonary testing might be necessary). In addition, these studies do not address the role of neoadjuvant chemotherapy which has been associated with improved survival in patients with locally advanced tumors and may take up to three months to administer prior to surgery. Furthermore, these studies do not address the delay that may occur from the onset of symptoms such as hematuria until the referral to a urologist who performs the tests to determine whether the patient has bladder cancer. What is known, however, is that invasive bladder cancers are often aggressive and unnecessary delay in diagnosis or from the time of diagnosis until definitive treatment is often associated with worse outcomes. So, the take home message for patients is to not delay in notifying your physician if you are experiencing symptoms that may be related to the discovery of a bladder cancer. For patients with non-muscle invasive bladder cancer (NMIBC), the timing of cystectomy presents a more difficult situation. In this scenario in which the bladder tumor is not invading the muscle but is recurring and threatening to progress despite aggressive resection and intravesical therapy, there is a general reluctance by patient and clinician alike to remove the bladder. While all options for intravesical therapy including chemotherapy and immunotherapy (BCG) are beyond the scope of this article, suffice it to say that most patients who have recurrent high grade Ta, T1 (lamina propria involvement) or CIS 6 months after either two 6-week courses of BCG or maintenance BCG are at significant risk for tumor progression to invasive disease which could result in death from disease.

In summary, patients with muscle invasive bladder cancer should undergo prompt consideration for radical cystectomy. Once the decision is made, the surgery should be performed without unnecessary delay. Best outcomes are reported if the cystectomy is performed within 3 months

of the diagnosis. This in no way should deter physicians or patients from important preoperative evaluations and/or second opinions regarding decision-making. Among patients with high-risk NMIBC, failure or recurrence after two-six week courses or maintenance BCG may be an indication for cystectomy. However, if salvage intravesical therapy is attempted, patients need to be followed closely to ensure that they are not progressing. Among patients with NMIBC, timely radical cystectomy should be considered an option in the setting of failed intravesical therapy.

Q. In terms of urinary diversions, aside from what is readily available today, are there any viable alternatives on the near horizon?

A. The past decade has seen significant advancements in bladder tissue engineering research, with the anticipation that it will ultimately provide functional tissue substitutes to replace diseased or dysfunctional tissues including bladder cancer. There have been some early reports of success with bladder augmentations and grafts using these techniques but to date there have been no attempts to use these methods in patients with bladder cancer requiring cystectomy. At present, the consensus is that progress being made towards bio-engineered bladders becoming a clinical reality once unresolved research and translational issues have been addressed. Currently, for patients undergoing cystectomy for bladder cancer there is no readily available substitute for bowel and there are no currently available artificial or synthetic bladders. For the foreseeable future, surgical improvements have been directed at laparoscopic and robotic-assisted radical cystectomy that may afford diversion via a smaller incision reduced convalescence and possibly improved functional outcomes. This is currently an evolving area of surgical research and will require performance in larger numbers of patients and longer follow-up before definitive conclusions can be made. However, the ideal bladder substitute remains elusive and the best current substitute regardless of choice of diversion is the patient's own small or large intestine.

Volunteer Corner

We all know that bladder cancer is one of those diseases that very few people know about. It's a common cancer with uncommonly low awareness amongst the general population. How many of you, when you or your loved one was initially diagnosed, heard the following from friends and family? "Bladder Cancer? Never heard of that before."

Those of us involved with BCAN are all too aware of this nasty cancer. And far too many people die every year...deaths that may have been prevented if people understood the symptoms so they could seek earlier medical treatment. We have an energetic group of volunteers committed to getting the word out across the country about bladder cancer because we know we can make a difference. Since our medical outreach campaign began 6 months ago, BCAN has mailed 2,100 brochures out to over 150 of the largest urology practices in the country. But we still have many states to cover and could use your help. If you can spare 5-6 hours a month to make

phone calls from your home and/or build our urology database, we could really use your help. Anyone who is interested, please contact our National Volunteer Coordinator, Allison Smith. Her email is allisonsmith@bcan.org

BCAN would like to acknowledge the following urology practices for adding the BCAN link to their website: Urology of Indiana (Greenwood, IN) and Urological Associates, Inc. (Evansville, IN).

It's Complementary

The good news is that, according to a national consumer survey conducted by the National Center for Complementary and Alternative Medicine (NCCAM) and AARP, almost two-thirds of people age 50 or older are using some form of complementary or alternative medicine. The bad news is that less than one-third of them talk about it with their healthcare providers. And of the group that does talk to their physicians, more than one-half said they, not their physicians, initiated the discussion.

The survey revealed some of the reasons why this important discussion does not occur. Most common reasons cited were:

- The physician never asked
- They did not know they should discuss CAM
- There was not enough time during the office visit

To help open this important dialogue, NCCAM has launched Time to Talk, an educational campaign to encourage patients, especially those 50 and older, and their health care providers to openly discuss the use of CAM. “In an era of genomics and personalized medicine, we need to remember that a key ingredient to good health care is the dialogue you, as a patient, have with your providers,” said Elias A. Zerhouni, M.D, director of the National Institutes of Health, of which NCCAM is a part. “And talking about what CAM therapies you use is an important part of that discussion. This is important for people of all ages.”

The Time to Talk campaign hopes to address the need for this dialogue to help ensure safe, coordinated care among all conventional and CAM therapies. “As frequent users of CAM, people 50 and older need to understand the importance of discussing CAM with their providers to ensure coordinated, safe care,” said Josephine P. Briggs, MD, NCCAM director. “Giving your health care providers a full picture of what you do to manage your health helps you stay in control.” For more information, visit <http://nccam.nih.gov/timetotalk> .

