

# Outlook

## Fall 2009



### President's Message

#### *BCAN Hosts Research Meeting*

In August, BCAN hosted the 4th Annual Bladder Cancer Think Tank, the only annual scientific conference in North America focused solely on bladder cancer. The primary objective of this meeting was to identify areas in which physicians and researchers who are devoted to improving the understanding and treatment of bladder cancer can focus future efforts for collaborative research. The 2009 meeting, which focused on “Novel Therapeutics and Strategies for Muscle Invasive and Advanced Bladder Cancer,” was a tremendous success. There were more than 70 attendees – urologists, oncologists, pathologists, radiologists, basic scientists – representing almost all of the major academic medical institutions in the United States (and several in Canada), along with survivors, bladder cancer advocates, and representatives from our pharmaceutical sponsors. There was great excitement and enthusiasm at our final working dinner as five different small “working groups” presented their proposals for launching and completing collaborative projects within the next two years. These projects include reviews of treatment patterns, survivorship support, biospecimen banks, data collection and management, and collaborative clinical trials. Planning is already underway for the 5th Annual Bladder Cancer Think Tank meeting, to be held in August 2010.

#### *Online Resources*

The website continues to be an essential resource for the bladder cancer community, and our online support community is taking on a life of its own (click on the orange button on your left to get to the support community). Now with over 800 members, this is an active group of survivors and caregivers who provide support, guidance and advice from a patient perspective to one another. Read in the Volunteer Corner section of the newsletter about the gatherings that have been organized by volunteers from our online community.

#### *Bladder Cancer Awareness Day*

Given the success of these local gatherings, BCAN is organizing a national “Bladder Cancer Awareness Day” to be held on a weekend in July. We will be asking volunteers to host similar picnics, events or activities at different locations around the United States and Canada. This type of grassroots effort should help gain some national media attention. To volunteer to help with a local event and local media attention, please e-mail Janet McIver, BCAN’s Information and Outreach Coordinator, at [volunteer@bcan.org](mailto:volunteer@bcan.org).

### *San Francisco Patient Forum*

We continue to host our regional educational patient forums, with our next program set for November 7 in San Francisco. We are very excited about our “multi-institutional” faculty, with doctors from UC San Francisco, Stanford and UC Davis participating. In addition, Gary Steinberg, from the University of Chicago and Chair of our Scientific Advisory Board, is serving as co-chair for this program. For more details, please click [here](#).

We welcome [Dr. Deborah Bradley](#), Assistant Professor of Medicine, Duke University, to our Scientific Advisory Board, and thank her for participating as our expert for this issue’s Ask the Doctor column.

I continue to be amazed as to how time rushes by and soon we will be entering the holiday season. May each of you be surrounded by love and hope each and every day.

Diane Zipursky Quale  
BCAN President

### **On Trial**

We are providing information on two different trials. The first is from the Southwest Oncology Group, “A Phase III Blinded Study of Immediate Post-TURBT Instillation of Gemcitabine versus Saline in Patients with Newly Diagnosed or Occasionally Recurring Grade I/II Superficial Bladder Cancer”. The second trial “Predicting Response to Intravesical Therapy with BCG,” is from M.D. Anderson.

A Phase III Blinded Study of Immediate Post-TURBT Instillation of Gemcitabine versus Saline in Patients with Newly Diagnosed or Occasionally Recurring Grade I/II Superficial Bladder Cancer

The Southwest Oncology Group (SWOG), one of the largest cancer clinical trials cooperative groups in the United States, is currently enrolling patients for a low risk bladder cancer trial – S0337, “A Phase III Blinded Study of Immediate Post-TURBT Instillation of Gemcitabine versus Saline in Patients with Newly Diagnosed or Occasionally Recurring Grade I/II Superficial Bladder Cancer”.

Immediate post TURBT (trans-urethral resection of bladder tumor) intravesical instillation therapy has been shown to reduce recurrence of completely resected low risk bladder cancer (LRBC). Despite this, intravesical instillation therapy is rarely performed in the United States. Gemcitabine has documented activity when administered systemically against advanced urothelial cancer and is well tolerated when given as intravesical treatment. Eligible patients are those with newly diagnosed and occasionally recurrent urothelial cancer, believed to be at low risk (G1, G2, stage Ta, T1) for progression. Eligibility for randomization will be based upon suspicion of study-eligible tumor grade and stage by the examining urologist, absence of prior grade 3, TIS, or T2+ cancers and no history of upper tract or prostatic urethral cancer. End points are time to recurrence and progression. For more information, please visit the SWOG website, [www.swog.org](http://www.swog.org), for a listing of institutions currently conducting the trial.

#### Predicting Response to Intravesical Therapy for Bladder Cancer

The majority of bladder tumors present as papillary lesions that can be resected endoscopically; however most of these tumors recur, and 10-20% progress to muscle-invasive disease. To reduce the incidence of recurrence and progression, patients are treated with intravesical immunotherapy using Bacillus Calmette Guérin (BCG). Although a large proportion of patients do respond to BCG, a significant number fail therapy. Studies have shown that if intravesical therapy fails and cystectomy is required, patients who undergo surgery within 24 months of initial diagnosis have improved survival. Thus early identification of patients in whom intravesical therapy will fail i.e., identification before the time of clinically apparent tumor recurrence, would permit earlier curative radical cystectomy and thus improve survival rates.

At present no reliable predictor of response to therapy yet exists. At MD Anderson Cancer Center in Houston, Texas, Dr Ashish Kamat and colleagues have instituted a prospective trial to identify markers to predict response to immunotherapy, so that we do not delay offering curative surgery to those who will ultimately need it. In this clinical trial, Dr Kamat will first evaluate whether the persistence of cytogenetically abnormal cells in the urine after initiation of intravesical therapy (molecular recurrence) predicts clinical tumor recurrence. Dr Kamat will also evaluate a panel of urinary cytokines to assess whether they correlate with patient response to intravesical immunotherapy. Finally, investigators will evaluate polymorphisms in genomic DNA isolated from peripheral blood of patients and correlate genetic profile with clinical outcome.

This article was contributed by Ashish Kamat, MD, Associate Professor and Fellowship Director, Department of Urology, M. D. Anderson Cancer Center. If you have questions about this clinical trial, you may contact Dr Kamat's research coordinators (Ms. Nancy Ainslie or Mr Roosevelt Anderson) at (713) 792-3250.

### Ask the Doctor

Our question for this issue of Outlook is answered by Dr. Deborah Bradley, Assistant Professor of Medicine, Duke University Medical Center. We sincerely appreciate Dr. Bradley sharing her expertise regarding systemic chemotherapy.

**Q: For a patient who is going to have a radical cystectomy for invasive bladder cancer, when is systemic chemotherapy appropriate? Should chemotherapy be given prior to the surgery or following the surgery? What are the pros and cons of each approach?**

The goal of radical cystectomy (surgical removal of the bladder) is to provide definitive treatment for patients with high-risk bladder cancer. In patients with muscle invasive disease, long term survival with cystectomy alone is only 30-80% depending on stage and other prognostic factors. Investigators have studied adding chemotherapy before cystectomy (neoadjuvant) or after cystectomy (adjuvant) to improve outcomes.

There are several potential advantages to each approach. Neoadjuvant chemotherapy has the advantage of immediately treating micrometastatic disease (cancer cells outside the bladder that are not large enough to be seen in scans) rather than waiting for recovery from cystectomy. Additionally, chemotherapy is better tolerated and drug delivery has been shown to be better prior to surgery. Since the primary tumor is still in place, it can be monitored and chemotherapy discontinued if there is evidence of disease progression. Information on how sensitive your tumor is to chemotherapy can be helpful to your doctor when making any future treatment decision. Cons to this approach include the fact that there is a subset of patients in which neoadjuvant chemotherapy is ineffective. If you are one of these patients, neoadjuvant therapy delays the potentially curative therapy of cystectomy. The biggest advantage to adjuvant therapy is that we can use the pathology results from the bladder and lymph nodes removed during cystectomy to better select patients for chemotherapy who are at highest risk for recurrence. Additionally, with adjuvant therapy there is no risk from delaying cystectomy. Although both are reasonable options to consider, neoadjuvant chemotherapy has stronger evidence from clinical trials supporting its use. In a large randomized phase III trial (317 patients from 126 institutions) cystectomy alone was compared to three cycles of MVAC (methotrexate, vinblastine, adriamycin, cisplatin) followed by cystectomy. There was a 25% decreased risk of death in patients treated with neoadjuvant chemotherapy without an increase in the risk of death or complications related to surgery. As a result, neoadjuvant chemotherapy followed by cystectomy with lymph node dissection has become the standard of care at many institutions for patients with muscle invasive bladder cancer.

Although MVAC is the standard neoadjuvant chemotherapy regimen, many patients are treated with a combination of GC (gemcitabine, cisplatin). This is because in metastatic bladder cancer, the combination of GC has been shown to work as well as MVAC with less toxicity and fewer side effects. It is assumed this is also the case in the neoadjuvant setting. Additional support for cisplatin-based neoadjuvant chemotherapy comes from a

meta-analysis of data from patients enrolled in 11 different clinical trials. Analyzing the data from all 3005 patients showed a survival advantage for patients treated with neoadjuvant platinum-based combination therapy. Although many patients with muscle invasive bladder cancer are treated with adjuvant therapy, the data supporting this approach is much weaker. The adjuvant trials have been smaller and have been criticized for methodological flaws limiting interpretation of results. In order to try to get around these limitations, data from many of these trials has been analyzed together in a meta-analysis of 491 patients from six trials. This meta-analysis did show a 25% relative reduction in risk of death with adjuvant therapy.

Despite the pros and cons of neoadjuvant and adjuvant chemotherapy, I believe neoadjuvant cisplatin-based combination chemotherapy followed by cystectomy with lymph node dissection should be the standard of care for treatment of muscle-invasive bladder cancer. In my opinion, chemotherapy should be offered before cystectomy to all patients who are thought to be able to tolerate cisplatin. Additionally, adjuvant chemotherapy should be offered to patients who have not received neoadjuvant chemotherapy but whose postoperative pathology finds tumors that extend outside the bladder or positive lymph nodes.

### Volunteer Corner



***North Carolina Picnic Attendees.***

BCAN's online support community is growing and thriving. This active group of over 800 survivors, caregivers, family members, and other loved ones provide peer support, guidance and advice from a patient and caregiver perspective to one another. It is wonderful to watch newly-diagnosed bladder cancer survivors receive support and have their questions answered by others who have been through what they are facing. This warm, welcoming community is available to survivors, caregivers, and loved ones 24 hours a day. (Click on the orange button on the left-hand side to get to the support community.)



***North Carolina Picnic Attendees***

40 members of this online support community gathered for a picnic in North Carolina on July 18th so they could finally meet in person after sharing so much with each other online. As you can see from the pictures, it was a beautiful event. One participant shared this impression: “As my husband and I mingled with others at the picnic, I was blessed by the encouragement and support of everyone gathered. As we joined hands in a prayer circle to pray for both those present and those who could not make it to the event, our spirits were lifted in unity. As the picnic in the Smoky Mountains’ breathtaking landscape came to an end, it was clear that we were living proof of the tagline for BCAN – ‘Together We’re Better.’” For the complete personal account of this event and its significance to the participants, please see below.

With the help of survivors who volunteered to tell their story, the event garnered some local and regional media attention. In addition to stories appearing in two regional newspapers and on the Asheville, NC TV news, participants from New Jersey and Florida also got their stories published, raising awareness of bladder cancer in their local areas.

Another face-to-face gathering took place this month when a dozen New England members of the online community met in Massachusetts for lunch and conversation.

Given the success of these local gatherings, BCAN is starting to organize a national “Bladder Cancer Awareness Day” to be held on a weekend in July. We are asking volunteers to host “family reunion-style” picnics, events or other activities for those affected by bladder cancer at different locations around the United States and Canada. BCAN will provide volunteers the tools to help get local media attention and also work to gain national media attention on bladder cancer awareness. To volunteer to help with a local event, please e-mail Janet McIver, BCAN’s Information and Outreach Coordinator, at [volunteer@bcan.org](mailto:volunteer@bcan.org).



*Veronica is pictured on the left, with other picnic attendees.*

### **Leading the Way to Bladder Cancer Awareness**

*Written by Veronica Tompkins*

(a previous version of this article was first published in the Waynesville, NC newspaper, The Mountaineer)

Twenty something years ago Linda Patton of Waynesville was diagnosed with bladder cancer and at the young age of 46 underwent a procedure to remove her bladder. Throughout the years, Linda had never met another person who had this type of surgery. She faced her journey with bladder cancer alone until this past July.

Fast forward to Saturday, July 18. That is when a group of almost 40 bladder cancer survivors and their spouses gathered to picnic on a ridge of the Smoky Mountains in order to meet each other for the first time face-to-face – myself and my husband included. The survivors came from all over — Florida, Georgia, Illinois, Ohio, Nevada, New Jersey – just to name a few of our home states. Some had a shorter drive, as they lived in North Carolina.

So you may be wondering how most of us found each other. As each of us learned of our diagnosis, we ventured online for answers to our questions. Somehow during our Internet searches, many of us ended up at the Bladder Cancer Advocacy Network site ([www.bcan.org](http://www.bcan.org)) and their online support community (click on the orange button on the left to get to the support community).

What we found was more than just information – we found a community of others with bladder cancer and their caregivers who understand what we’re going through. We found a source of strength – a never-ending supply of encouragement. But most importantly, we found a safe haven where we could discuss and ask personal questions about our condition and our bodies. Someone online said it best when they called us “intimate strangers.” Bladder cancer discussions are about as intimate as it can get. Many of us chat online daily and not just about our condition. Although we are separated by distance – we are united in experience and our goal to be cancer free.

Some locals found out about the picnic through media coverage. Nancy Parrish, of Waynesville, one of the key organizers of the event, wrote a letter to the editor of her local paper that caught the eye of Linda Patton. Nancy then invited Linda to join her for a story on Channel 13 news in Asheville. It was through these efforts that other

bladder cancer survivors in the area discovered our group, including an 82 year-old woman from Canton. All in all – four additional survivors joined the picnic because of the coverage in the press.

With the exception of the recent local coverage, the “unmentionable” nature of bladder cancer has limited press and public awareness of this life-changing disease. This was also the case with colon cancer prior to Katie Couric taking a lead in honor of her husband, Jay Monohan, and his courageous battle. As it says on the BCAN site, “Despite the fact that bladder cancer is the fifth most commonly diagnosed cancer in the U.S., it has been treated like the ‘elephant in the room,’ the disease no one wants to talk about in public.” It is time that bladder cancer becomes “mentionable” in the press as it affects so many people.

It is estimated that over 70,000 new cases will be diagnosed this year and over 14,000 people will lose their lives to this disease. That’s why Diane Zipursky Quale and her late husband, John Quale founded BCAN – to give a voice to those who fight bladder cancer. Awareness is key to increase federal funding for research devoted to the diagnosis, treatment and cure of bladder cancer. Although John died of metastatic bladder cancer in June 2008, it is important that his mission continue to live through those of us in the BCAN community he started.

No matter what treatment choices we make, or what urinary diversions we choose to replace our bladders, members of BCAN’s online community share one common goal – to be cancer-free. As I write this I am just two days away from my radical cystectomy – the surgical procedure to remove my bladder. At age 47 I am younger than most of my bladder cancer peers who have undergone this procedure. Nevertheless, I am grateful for the experience of all those who have gone before me on this journey and the amazing friendships I have formed in just six weeks of being part of this life-giving community.

When I met Linda Patton this weekend, the bladder cancer warrior who had her bladder removed over twenty years ago when she was my age, I got a personal dose of hope that there is life after radical cystectomy. As my husband and I mingled with others at the picnic, I was blessed by the encouragement and support of everyone gathered. As we joined hands in a prayer circle to pray for both those present and those who could not make it to the event, our spirits were lifted in unity. As the picnic in the Smoky Mountains’ breathtaking landscape came to an end, it was clear that we were living proof of the tagline for BCAN - “Together We’re Better.” Yes – together we are better and together we will continue to raise our voices until a cure for bladder cancer is found.

Veronica Tompkins is a 47 year-old mother of three who was diagnosed with bladder cancer in 2004, three years after being misdiagnosed with other conditions. She is now fully recovered from her July 22nd radical cystectomy and is partnering with her newfound friends at BCAN to coordinate a Bladder Cancer Awareness Day in July 2010. Veronica is volunteering for effort to raise public awareness of the symptoms of bladder cancer so that others can be diagnosed and treated early. She is also works to get the word out about BCAN and its online community so that those with bladder cancer will not face their journey alone.

## It's Complimentary

Anyone who has dealt with cancer, or any other major disease, knows how stressful the experience can be. Thoughts and emotions like anxiety, fear and uncertainty that creep into life every day can make treatment, healing and recovery very difficult, which is why it is critical to find ways to lessen the stress of an illness so as not to impede recovery.

And more and more evidence today says that music is one way to reduce that stress.

A new study from the University of Maryland says that listening to music that makes you happy can improve blood flow by increasing blood vessel dilation by 26 percent. How? Researchers speculate that hearing your favorite tunes triggers the release of endorphins, feel-good brain chemicals that signal the vessels to relax.

"Using music to help the ill has been employed for thousands of years, even though modern medicine is just starting to understand how it works," said Dr. Claudius Conrad, a senior surgical resident at Harvard Medical School. "Research has already shown that if you play a piece, like Mozart, at a certain slow beat, the listener will adapt their heart beat to the beat of the music."

While at the University of Munich, Dr. Conrad was able to show that critically ill patients required fewer sedative drugs when they listened to one hour of Mozart piano sonatas. As expected, the patients' blood pressures and heart rates eased with the music.

But Dr. Conrad was surprised to see that the patients also showed a 50 percent spike in pituitary growth hormone, which is known to stimulate healing.

There are many books in the marketplace that address the healing power of music, including "Music and Cancer: A Prescription for Healing" which was just released last month. A sampling of books on this subject can be found at [http://www.amazon.com/s/ref=nb\\_ss?url=search-alias%3Dstripbooks&field-keywords=music+and+healing&x=0&y=0](http://www.amazon.com/s/ref=nb_ss?url=search-alias%3Dstripbooks&field-keywords=music+and+healing&x=0&y=0).

Clinical studies and anecdotal evidence from music therapists suggest that the sound of music can help manage pain, decrease nausea during chemotherapy, relieve anxiety, lower blood pressure, ease depression and shorten hospital stays.

So what type of music is best?

"Many years of research have shown me that there is no set prescription, no particular piece of music that will make everyone feel better or more relaxed," says Suzanne Hanser, EdD, a music therapist at Dana-Farber Cancer Institute, in an article published in Prevention magazine. "What counts is familiarity, musical taste and the kinds of memories, feelings and associations that a piece of music brings to mind. The key is to individualize your musical selections."

Dr. Hanser says that you can feel refreshed after listening to music for as little as 10 minutes. Just find a spot where you can sit or lie down in a comfortable position, in a place where you will not be disturbed. Then, after listening for a few minutes, add a relaxation exercise by starting at your feet, gently tightening, then relaxing your muscles.

"Afterward, you may find that you're able to think more clearly and approach the rest of your day with a more positive, relaxed outlook," she says.

So kick off your shoes, grab your favorite CDs and take a few minutes for yourself to enjoy some tunes that you love. You may be doing more good for yourself that you know.