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James (Jim) Patrick Zito

I don't think people take bladder cancer seriously enough. Many think bladder cancer is just a disease of older people. They can have their bladder removed, and they will have a diversion and then be just fine after that. That's not always true. My husband's mother was diagnosed with bladder cancer in 2002. She had her bladder out; she has a urostomy bag. Now she's 95 years-old and still living. She never had chemo. She never had anything. She survived. I think a lot of our friends and relatives just thought it was going to be the same for Jim. That's just not the case with bladder cancer. It's a sneaky, devious, evil disease. More research funding and education are desperately needed to beat it. It does not attract the attention and research dollars that other cancers do.

"Jim always had hope. He was always so positive. Never give up hope!"

In October 2014, Jim had a TURBT. They determined that he did have muscle invasive bladder cancer, and the urologist immediately referred us to UT Southwest in Dallas, TX, home of the Harold C. Simmons Comprehensive Cancer Center, an NCI-designated comprehensive cancer center. The oncologist at UT Southwest presented us with options for treatment, which were few and pretty straightforward. Jim needed to start chemo as soon as possible, and follow up with a radical cystectomy. We didn't hesitate and were very aggressive in how we approached his treatment.

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OUR MISSION

To increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community.

A note from Andrea...



This fall's issue of The Beacon is a tribute to research which is the third leg of the Bladder Cancer Advocacy Network's (BCAN) mission to increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community.

We open with an article about one man's journey and fight against bladder cancer which is chronicled by his wife, Lynn. In a letter to BCAN, Lynn shared information about her

husband Jim and his decision to enroll in an immunotherapy clinical trial. She stated, "It's too late for Jim, but a cure has to be found for this monstrous disease, so that other patients and their wives, husbands, parents, sons, daughters, family members and friends don't have to suffer." Lynn's letter was so inspiring to us; we reached out to her and asked that she share it with you.

BCAN routinely lists clinical trials on our website so that the bladder cancer community can easily find trials that are happening near you. Although Jim lived in Texas, he was part of a National Institute of Health (NIH) clinical trial in Bethesda, MD, led by Dr. Andrea Apolo, who serves on BCAN's Medical Advisory Board. In this issue of The Beacon, you will also get a glimpse into clinical trials from the physician's vantage point as Dr. Apolo shares what she learned by working with Jim.

Through the generosity of donors like you, BCAN's research program continues to grow, and we are happy to share the 2016 Young Investigator and Bladder Cancer Research Innovation Award recipients in this issue.

Finally, we feature a snapshot of 2016 events across the country in pictures. You can help us to end bladder cancer and fund much-needed research by signing up now for the 2017 AmpUp! Walk/Run to end bladder cancer which launches this month.

Warmest wishes,



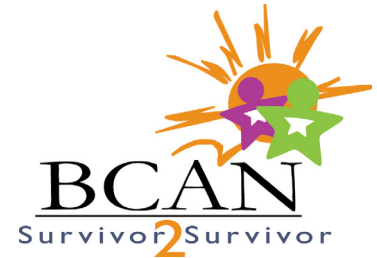
Andrea Maddox-Smith
BCAN Chief Executive Officer

P.S. BCAN is relentless in the fight against bladder cancer and life-changing research is making a difference. But we can't fight this battle without you. Consider a gift to the Bladder Cancer Advocacy Network in support of research. It could save someone's life.



Looking for information
and support?

Visit www.bcan.org



Every Patient Matters

Mr. Z was enthusiastic about participating in the clinical trial. Although he had advanced metastatic disease and was experiencing pain, we hoped he would benefit from our treatment, since he was otherwise



healthy and had a strong support system and a positive outlook. Unfortunately, we cannot predict which patients will respond to therapy and do well on trial, but we are always optimistic about all our patients on study.

Mr. Z. had a very aggressive cancer that did not respond to treatment. Other patients who were not as healthy did respond and are still in the trial. We don't know why some patients on the trial do not respond. It could be the genetic

makeup of the tumor, such as its DNA and RNA, or the presence of certain proteins on the surface of the tumor. We hope for a 100% response rate, but we know a certain percentage will respond and others won't. Even when a patient doesn't respond, we still learn a lot by analyzing the clinical and biological features of that patient's tumor.

We are trying to learn more about overcoming resistance to certain therapies, including immunotherapy, and how we can prime a tumor to make it more susceptible to immunotherapy. Is it combination therapies? Selecting patients with certain genetic traits? All these data are evaluated in a clinical trial to help get higher responses in subsequent clinical trials.

Patients live on forever when they participate in a clinical trial. They are never forgotten.

Researchers and scientists often forget to tell clinical trial patients how truly valuable they are. We use data and images from patients like Mr. Z. for teaching and understanding patterns of disease. We use their tumors as controls for laboratory experiments or clinical assays. Sometime we grow their tumors in the laboratory using cell cultures and mouse models to study additional therapies or to just understand the molecular drivers of the tumor.

Mr. Z. was part of a clinical trial that is still ongoing. We review his demographics, all his documented side effects, and

his radiographic scans every time we analyze the clinical trial data.

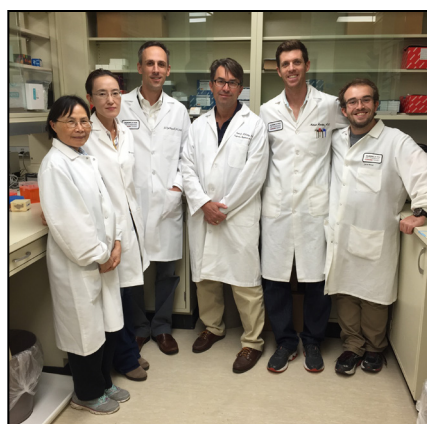
Patients don't usually see the manuscripts that come from clinical trial research in which they participate or the laboratory experiments that we were able to conduct based on their tumor. Patients don't see the radiology images we use to follow tumors and how we review them over and over again to detect patterns of metastases or to find better methods of assessing response to therapy. Every time I use data derived from a patient in one of our clinical trials, I think about them; I think about their family, their loved ones. I remember the conversations we had while they were in clinic about politics, travel and the hobbies they enjoyed. I have memories of hundreds of study patients, and I am very grateful to each of them for their altruistic contribution to my research.

We would never get any drug approved if not for patients who were part of the trials.

I just want to reemphasize how important it is to advance bladder cancer research by participating in clinical trials. We learn about tumors, about therapeutic efficacy, toxicity, genetics, and more. It is important to be realistic and to be transparent. Patients with advanced disease, in particular, don't always realize how important it is to participate in a clinical trial.

Putting Your Research Dollars to Work in 2016

BCAN is committed to supporting bladder cancer research. Our 2016 Bladder Cancer Research Innovation



Dr. David McConkey
and his research team

Award was presented to David McConkey, MD, PhD, Director at the Johns Hopkins Greenberg Bladder Cancer Institute in Baltimore, MD. His study "Targeting FGFR3 in muscle-invasive bladder cancer" will run for two years.

Continued on Page 6

Jim's Story - Continued from Page 1

We pushed to get everything started as soon as possible. After his cystectomy and neobladder, early in 2015, we learned that his cancer had spread. He began chemotherapy and soon had no evidence of disease until 'something' showed up at the end of November 2015. Jim had started a course of radiation treatments because his cancer had metastasized into his lower spine and he was experiencing a tremendous amount of back pain.



**Thank you
for your support.
We will see you in 2017!**

Top 5 Teams in 2016

Team Coffin	Lehigh Valley, PA
Team Konstant Fight	Chicago, IL
Friends and Family of JCQ	Washington, DC
University of Chicago	Chicago, IL
Fox Chase Cancer Center	Philadelphia, PA

Genentech
A Member of the Roche Group



Having spent 20 years as a pharmaceutical rep, I was very familiar with clinical trials and their opportunity to access promising new therapies that aren't yet available to the general public. We looked into different trials using resources available on the BCAN.org site as well as on clinicaltrials.gov. Jim's oncologist in Texas had contacted Dr. Andrea Apolo, at the National Cancer Institute, and arranged for us to meet with her at the National Institute of Health in Bethesda, MD, to screen him for acceptance into an immunotherapy clinical. They accepted Jim into the trial, and we began to travel to the NIH every three weeks for treatment.

Although we were seeing some positive response during the clinical trial, time ran out and this horrific disease ultimately overwhelmed. After a valiant 21 month battle with bladder cancer, Jim passed away on July 13, 2016. He will be deeply and forever loved and missed by myself, his family, friends, colleagues and his devoted 4-legged fur family.

I believe that every patient should have an advocate with them at all appointments, not just for support, but to be their eyes and ears as well. There is an immense amount of information to process and critical decisions to be made. Things can move very quickly and having an advocate along during appointments for support, and to help clarify, is vital. Jim and I committed to going through his treatment together, as a team. I was with him during every appointment and procedure throughout the course of his therapy.

I realize that I was fortunate, and not everyone can do

that, but I would urge anyone going through cancer to find a surrogate advocate for times when the spouse or partner is not able to go with the patient. I also believe that there needs to be a team approach when treating cancer. No matter how brilliant the primary oncologist is, there are times during treatment where additional specialists might be of great benefit to the patient. One important area for some patients is pain management. I would strongly suggest bringing a Pain and Palliative Care Team on board as early in treatment as possible. They are the specialists best equipped to deal with the often excruciating pain and other symptoms associated with cancer and its treatment. Jim and I were fortunate to have had a great P&PC team at UT Southwest. I only wish that we had found them earlier in his diagnosis and treatment.

Finally, never give up hope and be proactive about treatment. Keep moving forward. Don't stop.

Always think ahead to what your next option might be. Do a lot of research and seek out promising new courses of therapy. Look into clinical trials. There is so much happening today in cancer research. BCAN is a tremendous resource for information

and support. My husband and I both benefited immensely from the BCAN website, and I still do. We spent a lot of time on the site researching and reading about other people's experiences and trials.

Above all keep the faith.
Sincerely,



Lynn and Jim

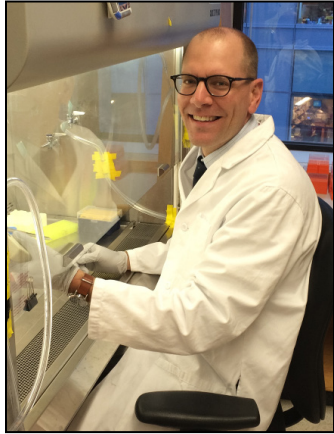
Sym C. Zito

To read more about Jim's bladder cancer story, visit:
www.bcan.org/never-give-up-hope/



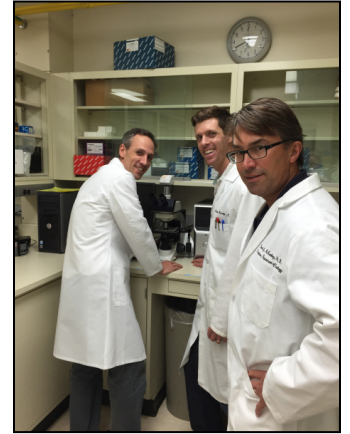
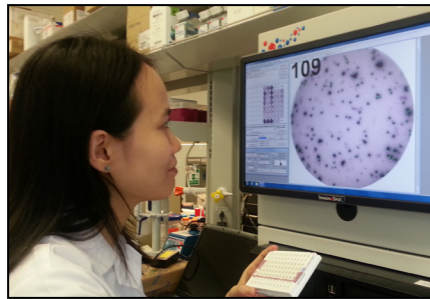
port helped BCAN fund two one-year Young Investigator Awards. The “Identifying Genomic Determinants of Chemo-radiotherapy Response in Muscle-Invasive Bladder Cancer” research of Kent William Mouw, MD, PhD, at Dana-Farber Cancer Institute, will leverage new genomic techniques to better understand how these biomarkers can benefit muscle-invasive bladder cancer patients treated with combined modality therapy.

Niannian Ji, PhD, from the University of Texas Health Science Center at San Antonio will provide key insights into BCG efficacy in treating bladder cancer. She will establish a framework for rapid development of BCG combination strategies to combat BCG resistance in bladder cancer patients in her research on the “Role of antigen-specific immunity in BCG therapy for bladder cancer.”



“I am incredibly grateful to receive a 2016 BCAN Young Investigator Award. The award will be instrumental in supporting our study to identify predictive biomarkers of treatment response in muscle-invasive bladder cancer. We are very thankful for BCAN’s generous support of our work!” - Dr. Mouw

“BCAN provides significant resource and support for my research, particularly with the advanced and high-throughput immunological assays that allows the monitoring of immune response from clinical samples of bladder cancer patients or mouse models.” - Dr. Ji



“We are absolutely convinced that FGFR3 is an excellent therapeutic target and feel a sense of urgency in defining the biological underpinnings of FGFR3 dependency and acquired resistance to clinically available FGFR inhibitors... We are so appreciative of the support we are receiving from BCAN for this incredibly important project.” - Dr. McConkey

Bladder Cancer Think Tank - the nation’s only scientific meeting

The 11th Annual Bladder Cancer Think Tank brought together over 200 clinicians, scientists, and patient advocates, all with the goal of collaborating to move bladder cancer research forward. Started in 2005 with less than 40 urologists, the 2016 Think Tank in Denver also included medical and radiation oncologists, researchers and social scientists from 31 states

and eight countries. The one thing that grounds this important bladder cancer research meeting are the patient advocates who bring your voice and your story into collaborative discussions on the latest advances in bladder cancer. The keynote address about “Integrating Palliative and Oncology Care in Patients with Advanced Cancer” by Dr. Jennifer

Temel of Massachusetts General Hospital, kicked off a meeting that addressed many issues affecting the quality of life for those with bladder cancer.

While most think of palliative care as part of hospice or end of life care, palliative care



A Community Urologist Speaks About How BCAN Helps His Patients

Dr. Nilay Gandhi, a community urologist at Potomac Urology in Alexandria, Virginia, began in the field with pediatric urology. "Seeing the differences that you can make in a child's life with different reconstructive surgery can greatly impact them on a day-to-day basis," he noted. He truly became interested in bladder cancer research via his long-time mentor: "Dr. Donald Lamm helped to revolutionize bladder cancer treatment with BCG instillations and pioneered a lot of that research. I was able to gain a sense of the impact of bladder cancer but also the effect of research and awareness that can ultimately lead to greater outcomes with patients." Trained at the prestigious Brady Urological Institute at Johns Hopkins University, Dr. Gandhi has also worked with many well known bladder cancer experts (Dr. Mark Schoenberg and Dr. Trinity Bivalacqua), investigating the impact and effects of neoadjuvant chemotherapy on bladder cancer.

Dr. Gandhi sees one of the challenges for bladder cancer as access to care. "Bladder cancer is one of the most expensive disease processes due to the frequent need for surveillance cystoscopies or biopsies that require regular follow-up. A lot of patients aren't able to take that many days off to have these done consistently. They may also tend to have other co-morbidities or may be on different medications that can affect when to do biopsies, all of which can effect outcomes of care."

The BCAN Survivor 2 Survivor program is one that Dr. Gandhi recommends to his patients. "I can outline what to expect, what sort of treatments, what their schedule will look like. But it means an entirely different thing to have someone who's gone through these treatments, who's faced these questions and concerns everyone has about work or finances or schedules, and to have made those treatment choices and have them discuss that with the new patients. To be able to talk about what their diagnosis has meant from a personal level, from a financial level, from a family/social level, how it has entirely impacted their life and how they've been able to handle that.



Nilay Gandhi, MD

"I think the Survivor 2 Survivor program is invaluable."

Dr. Gandhi maintains his strong interest in bladder cancer research and currently conducts clinical trials in his practice. BCAN is excited to have him involved in the 2017 AmpUp! Walk/Run to End Bladder Cancer in Washington, DC, next May.

dedicated solely to advancing bladder cancer research!

experts focus on providing relief from the symptoms, pain, and the physical and mental stress of a serious illness. The goal of such therapy is to improve the quality of life for both the patient and the family.

The initial panel presentation focused on the high cost of cancer treatment and highlighted ways this "Financial Toxicity" is measured. Experts discussed changes needed to ease this burden from within the US healthcare system.

A urologist, a medical oncologist, a radiation oncologist and a patient walked up to a podium....

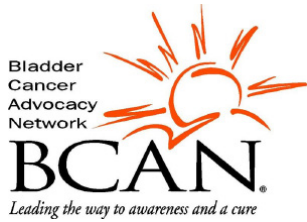
While this might look like the start of a joke, the reality shared in the "Bladder Preservation* Updates..." panel, is that some patients who have muscle invasive bladder cancer, under the right circumstance, who have access to a multidisciplinary health care team, may be able to avoid radical cystectomies.

After provocative discussions on topics ranging from improving outcomes with nutrition to optimizing mouse models for bladder cancer research and presentations of BCAN sponsored research, the final science focused panel explored the "Translational Impact of Stem/Progenitor Cells in Bladder Cancer."



Think Tank participants left the mile high city inspired, connected through new and strengthened collaborations, and motivated to keep working to improve the understanding and treatment of bladder cancer. We can't wait to see what happens next year when the Think Tank convenes in Charlotte, NC.

*Watch BCAN Co-Founder Diane Quale interview experts on the Multidisciplinary Approach at www.bcan.org/learn/educational-programs/videos/



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