



*"When can we start,
and how can I help."*

In memory of Pat Boumansour
1945-2017

I always describe BCAN as a community, made up of patients, family members, friends and medical professionals, working together to make a difference in the lives of all of us who have been impacted by bladder cancer. Pat Boumansour was a vital member of this community and her death on July 6 is a great loss to us all. Pat shared her vitality, strength and compassion with thousands as a volunteer for BCAN. She spoke frankly and candidly about sexuality following her bladder removal surgery during the 2013 Bladder Cancer Think Tank, challenging the medical community to pay more attention to the needs of women.

Pat's death is a reminder to each of us to live each day to the fullest, as she did. In addition, as her husband Mike describes, "her death is a symbol as to what each person can do to help others, as she did. Like casting a stone in a pond, each ripple causes another ripple to form, each person informs other people. Be that stone in the pond of fear and frustration. Make a difference." Pat made a huge difference and she will be very much missed.

- Diane Zipursky Quale

grandchildren, took up a lot of her time. She loved cycling, hiking and was an avid reader as well as a great Scrabble player. She made friends easily.

None of those things changed when approximately nine years ago, 65-year-old Pat, an avid long distance cyclist, and exercise enthusiast, began to have urgency and frequency issues with her bladder. She visited several general practitioners. They told Pat it was a UTI or "runners bladder." After several years, Pat's suddenly elevated blood pressure led to an ultrasound. It showed one kidney blocked. At that point, a referral to the urologist ended with a stage T3 bladder cancer diagnosis. After neoadjuvant chemotherapy and a radical cystectomy, post-op pathology showed one lymph node with malignant cells. Pat then participated in a clinical trial.

At that time Pat became very active in BCAN as well as University of Michigan programs to assist other bladder cancer patients. As her husband Mike shares,

"Her personal experience, intelligence and ability to communicate effectively and warmly, left those she touched informed and thinking positively again about life ahead."

Pat and Mike Boumansour celebrated their 50th wedding anniversary in 2016. They have three sons and seven grandchildren. As the matriarch of the family, Pat's



Pat did so much for BCAN. **Patbfit**, as she was known in the BCAN Inspire online support community, was the epitome of a patient advocate. She provided comfort, direction and support to those she reached through Inspire. She contributed to our educational resources by helping create our original "Get the Facts" tip sheets and sharing her bladder removal experience in our "New Normal videos." She helped raise bladder cancer awareness in the greater Detroit Area through her participation in the local BCAN Walks

for Bladder Cancer. As a volunteer with the BCAN Survivor 2 Survivor program, she would spend hours helping people in crisis, guiding them through terror and depression.

Pat never let bladder cancer define her, and following her surgery, returned to a "new normal" and filled her life with family, friends, biking, hiking and other activities.

Pat and Mike retired a couple of years ago, moving from outside Detroit to Palm Coast, Florida. She was a "model survivor," never missing a required "follow up" with her medical team. As Mike explains, "Pat had regular scans over the seven years after her surgery. These were visceral scans monitoring the pelvic area to the lungs. Each time we breathed a sigh with the 'all clear' report." Things changed in October 2016, when Pat began to have hearing issues in one ear. "Gradually over the next few months, she began to have difficulty recalling words at a rate that became increasingly severe. We went to an ENT doctor who indicated that the

cilia in her right ear were no longer functional. Pat's hearing loss was permanent. He later did a scan on her brain and discovered a very large tumor that had been there for some time. On April 4th, she had surgery to remove most of the tumor. Whole brain radiation followed. The pathology report indicated it was indeed bladder cancer that had metastasized. Pat lived about three months following her brain surgery."

As noted by Pat's urologist, Dr. Cheryl Lee,

"Losing Pat to bladder cancer because of brain metastases, after more than five years of being cancer free, was an extremely uncommon event and a shock to our entire community."

Of the individuals with muscle-invasive disease that are free of cancer at five years, only a small percentage (<10%) will develop a recurrence later in life. When cancer returns after surgery, it typically appears in the lymph nodes, lung, bone, or liver. Historically, the rate of urothelial bladder cancer that spreads to the brain is quite low (1-3%)."

People are not statistics, and while Pat's bladder cancer recurrence in the brain was unusual, it reminds us that despite the advances being made in bladder cancer diagnoses and treatment, we still have so much more work to do. How can

we best honor Pat's memory and her contributions to our community? Mike Boumansour implores, "Right now more energy and funds should be directed to education so that the disease can be contained and treated with the drugs and protocols available today. Pat's death was the confluence of misdiagnosis at least twice. It should not happen. But BCAN can make a difference. As Pat would say, 'When can we start, and how can I help.'"



Pat and her husband, Mike