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*Jeff and Crystal with their children*

While bladder cancer occurs more frequently as we age, the BCAN community has individuals of all ages, gender, and races. Only 30 at the time of his diagnosis, Jeff is not your typical bladder cancer patient. Four years and three children after his diagnosis, Jeff views his experience as an opportunity to raise awareness and funds to support research to end bladder cancer.

In a recent interview, Jeff explained: "After examining me, the doctor said 'I think you have cancer. We're going to set you up to go see a specialist', and he walked out of the room." That specialist thought he found kidney stones in my bladder. And they set up a routine scope to take a look.

But Jeff didn't have kidney stones; it was cancer as the first doctor predicted. Bladder cancer. After his tumor was removed, Jeff and his wife, Crystal, discussed his treatment options with his doctors. Because they had been trying

to have children, they decided not to have radiation or chemo at that time. They wanted the best chance to have kids before going further with his treatment. "Bladder cancer ended up as a blessing in disguise. Because of my doctor's connections, we got right in to see a fertility specialist that otherwise had a 2-year waiting list. Four years later we've got three wonderful children. I had to get bladder cancer to move down the path to having these children and building a great family."

When initially diagnosed, Jeff didn't receive specific information about bladder cancer. There were no support groups nearby.

**"I don't have family and friends that have bladder cancer. The internet led us to BCAN."**

"I realized we needed to start increasing awareness in the Greater Omaha area because people didn't know or talk about bladder cancer."

*Continued on Page 6*

## OUR MISSION

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

Contact Us: 1-888-901-BCAN

WWW.BCAN.ORG

info@bcan.org

## A note from Andrea...



I hope that 2017 is off to a wonderful start for you. This year can mean a life of uncertainty for the individual and families confronted with bladder cancer, and naturally, you'll want to learn more to understand what this diagnosis entails. Thanks to you, BCAN can provide the much needed educational program services and cutting-edge research necessary to combat the disease. We also work to educate national and state policy makers, the medical community and the general population about the nature and extent of bladder cancer in the United States.

This is going to be a big year for BCAN. You will see many exciting advancements coming in our resources and services, and we can't wait to share them with you. Thanks to your support, this Spring you will see a newly designed custom website making it easier for patients to navigate while facilitating an enhanced user experience. There are changes coming to the Clinical Trials Dashboard which will allow patients to create accounts and

save the trials they are most interested in pursuing. Also new this year, BCAN is launching a full service Planned Giving site which emphasizes gifts anyone can make to support the bladder cancer community.

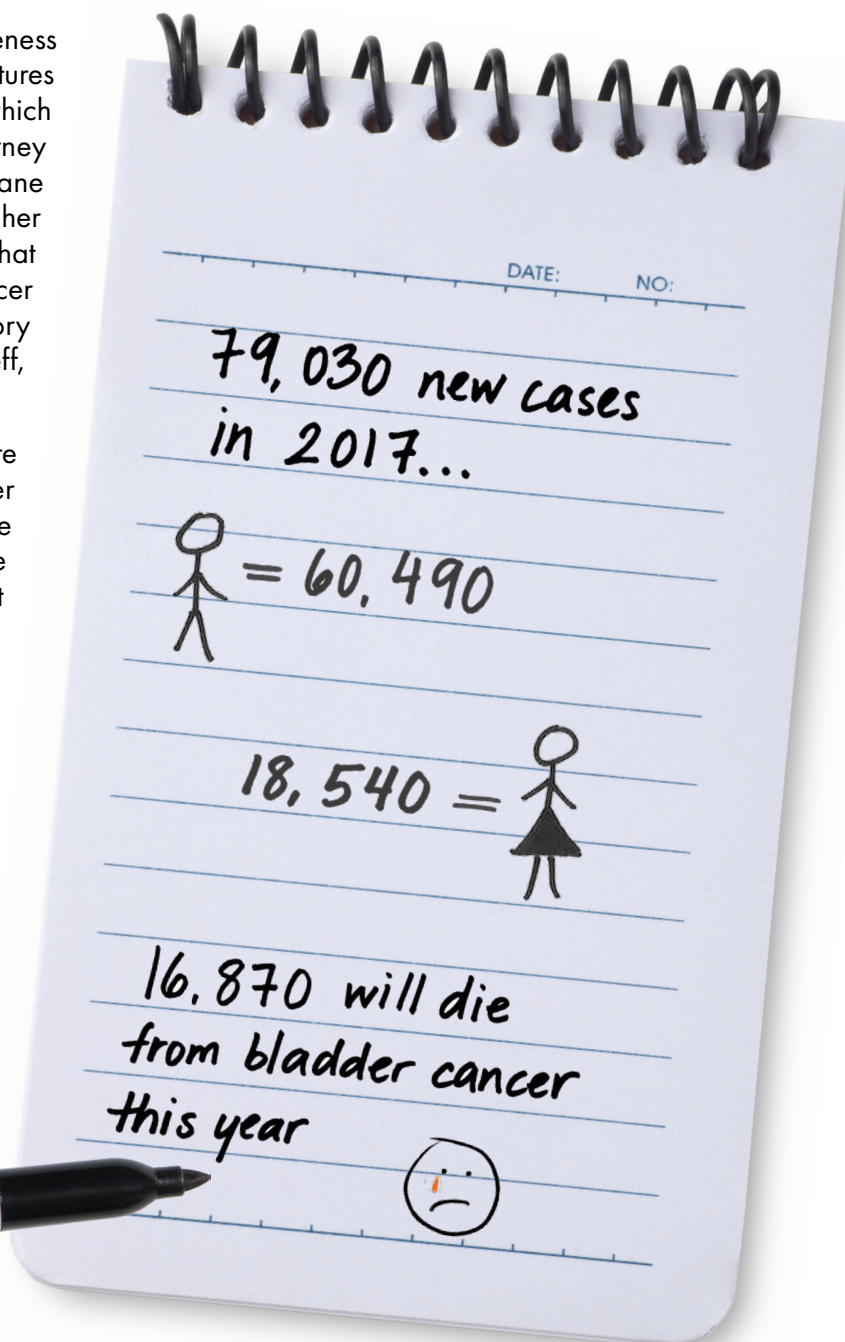
This issue of *The Beacon* focuses on raising awareness of the fifth most common cancer in America. It features the launch of the "My Bladder Cancer Story", which encourages patients and families to share their journey so that others realize they are not in this alone. Diane Zipursky Quale, Co-Founder of BCAN, shares her inspiring story about her husband John and how (at that time) the lack of resources available to bladder cancer patients led to the creation of BCAN. Our cover story features an unlikely bladder cancer patient named Jeff, who sees his diagnosis as a blessing in disguise.

Finally, we feature information on our only signature fundraising event, AmpUp! Walk/Run to End Bladder Cancer which is taking place at 29 sites across the country this spring. Your support helps us to achieve our mission to increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community. I am incredibly excited for the year to come. Together, we can accomplish great things on behalf of the more than 500,000 Americans living with bladder cancer and all who will be diagnosed this year.

Thank you again,

A stylized, handwritten signature in black ink, appearing to read 'Andrea'.

Andrea Maddox-Smith  
BCAN Chief Executive Officer





*"Statistics are people  
with the tears wiped away."*

While knowing the numbers can help to raise awareness of the disease, BCAN is launching the "My Bladder Cancer Story" campaign to put the people back behind the statistics. Each new case of bladder cancer is one too many. "It is our hope that this campaign will be an avenue for those affected by bladder cancer to share their stories and to be a voice for those who, for far too long, have felt alone in their fight against this

disease," said Andrea Maddox-Smith, BCAN CEO.

The "My Bladder Cancer Story" campaign features personal stories from patients, survivors, caregivers and loved ones of those who have passed away from bladder cancer. BCAN will share submitted stories through multiple platforms including social media, newsletters, marketing materials, BCAN.org and more. It's time to talk about bladder cancer!

Learn more and share your story, visit: [www.bcan.org/bladder-cancer-story/](http://www.bcan.org/bladder-cancer-story/)

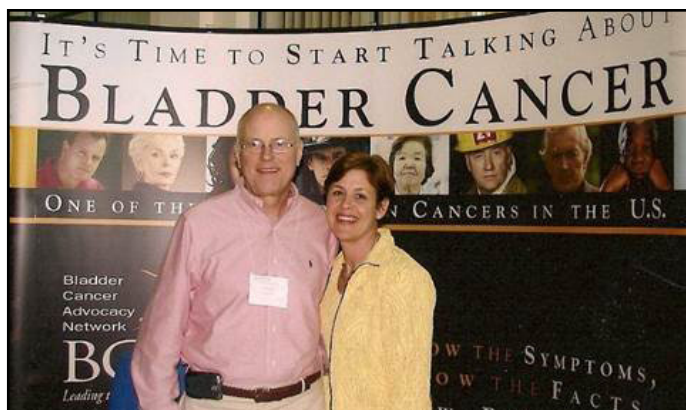


## My Bladder Cancer Story | BCAN Co-Founder Diane Zipursky Quale shares her story

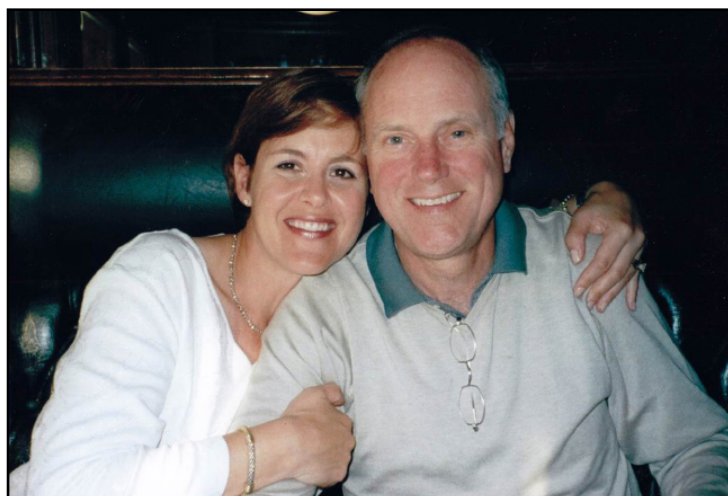
**M**y husband, John Quale, was diagnosed with bladder cancer in May 2000 when he was 53. We had never heard of the disease before, nor did we know of anyone else who had it. John's cancer first arose in his renal pelvis, requiring removal of his right kidney. Initially, we were content to simply follow the advice of our doctors. We had no clue that bladder cancer has a very high recurrence rate and that our doctors fully expected it to return.

Eight months following his surgery, doctors discovered multiple tumors in John's bladder. Further tests indicated the cancer had metastasized to his liver and lymph nodes. We were dismayed and frightened to learn about the limited treatment options available and recognized that we need to be our own advocates. We discovered that bladder cancer was at the bottom of research funding at the National Cancer Institute, limiting opportunities for research advances.

After 6 months of chemotherapy, there was "no evidence of disease" and John's oncologist described it as a "unique response." We celebrated, yet we understood the importance of "the now," recognizing that our world could change again at any moment.



Over the next four years, recurrent tumors in John's bladder required multiple resections, intravesical treatments, and combined chemotherapy and radiation. We became increasingly frustrated at the lack of attention given to bladder cancer. In the spring of 2005, we decided to change the



John Quale and Diane Zipursky Quale - Co-Founders of BCAN

national conversation about bladder cancer. With the help of friends and family, and strong support from the medical community, BCAN was born.

BCAN's mission addresses the areas in greatest need of attention: **raising awareness** about bladder cancer-- because the first time an individual hears about this very common disease should not be at initial diagnosis; **advancing research** for better treatment options so more lives would be saved; ensuring that patients and families had **access to information** so that they could take an active role in treatment decision-making, and that no one diagnosed with bladder cancer would ever feel alone in the journey.

John's recurrent bladder tumors finally required removal of his bladder in September 2006. The surgery went without surprise. But when his cancer came back in 2007, there was no chance of beating it back again. There were no clinical trials to join, no second line therapies to try. My husband died on June 29, 2008. John was a remarkable man, who lived his life to the fullest, never letting his disease define him.

**John would be so proud to see the BCAN community today. Bladder cancer is now "on the map."**

*Continued on Page 6*



**A gift anyone  
can make?  
What's not  
to like?**

It's true.

By making us the beneficiary of your will or revocable trust, you'll help guarantee our financial strength tomorrow, without affecting your cash flow or your family's financial stability today.

It's an easy gift to help those affected by bladder cancer for generations to come.

#### **Interested?**

For more information about this and other planned giving opportunities, visit:

[bcan.plannedgiving.org](http://bcan.plannedgiving.org)

Or contact:

Anita Parker

[aparker@bcan.org](mailto:aparker@bcan.org)

**888-901-BCAN x 202**



## **A Lasting Tribute | Special People Deserve a Special Gift**

You've read about how Diane continues to honor John's life through the work of BCAN. Is there a special person in your life that deserves to be recognized? You may have thought about honoring their life and legacy but wonder how. If you are looking for a meaningful way to honor that special loved one, consider making an endowment gift to the Bladder Cancer Advocacy Network in that person's name. Many people appreciate the opportunity to make a gift in honor of someone special, knowing that their donation honors the life of that individual, while also supporting a cause which he or she holds dear.

The idea of making a tribute gift may feel intimidating. Perhaps you think it's something only the ultra-wealthy do. But actually, an endowment gift is simpler and more accessible than many people realize. Because endowed funds are truly forever funds, they make a meaningful tribute gift that will honor the name of your loved one forever.

### **What Is an Endowment?**

An endowment is a permanent fund in which the principal donation is maintained intact; it is invested to create a perpetual source of income for the Bladder Cancer Advocacy Network. You can set up a fund for general support or for a specific purpose or program.

### **Interested?**

There are many creative, long-term giving strategies, and we would be happy to talk through the options with you. We are also available to collaborate with your financial and legal advisors if you'd like to use your will or estate plan to make your tribute gift. Please contact us. We're here to help every step of the way.

For more information, visit [www.bcan.plannedgiving.org](http://www.bcan.plannedgiving.org) or contact:  
Anita Parker, Director of Development at [aparker@bcan.org](mailto:aparker@bcan.org) or (301) 215-9099, ext. 202.

*This publication is intended to provide general gift planning information. Our organization is not qualified to provide specific legal, tax or investment advice, and this publication should not be looked to or relied upon as a source for such advice. Consult with your own legal and financial advisors before making any gift.*





Join the Fight Against Bladder Cancer!  
Register Today at [www.ampupbcan.org](http://www.ampupbcan.org)

**Contact:**

Rebecca Yannopoulos  
301-215-9099 ext. 206  
[walk@bcan.org](mailto:walk@bcan.org)

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## Where we walk

**Baltimore, MD**

**Boston, MA**

**California**

- San Diego
- San Francisco

**Central Ohio**

**Chicago, IL**

**Greater Omaha, NE**

**Hampton, NH**

**Jersey Shore, NJ**

**Nashville, TN**

**New York**

- Albany
- Central Nassau Co.
- New Paltz
- New York City

**North Alabama**

**Oklahoma City, OK**

**Pennsylvania**

- Central PA
- Lehigh Valley
- Philadelphia
- Pittsburgh

**Phoenix, AZ**

**Richmond, VA**

**Seattle, WA**

**Southeast Michigan**

**Texas**

- Corpus Christi
- Dallas/Forth Worth
- Houston

**Triangle, NC**

**Washington DC**

We walk in  
support of ...

We walk in  
honor of ...

Why  
we  
walk

We walk in  
memory of ...

We walk  
as survivors!

### We need volunteers!

Join a planning committee or volunteer to help on walk day.

### **BCAN Do It Yourself Fundraising**

Host a fundraising event, start a grassroots fundraising campaign with email or take on a personal challenge of your choice. Kick off a DIY fundraising activity and invite others to join you!

Activities can include golf tournaments, dinner parties, bake sales, simply asking your friends and more!

**Get started today! <http://support.bcan.org/diy>**

When I first learned about the AmpUp! walk it sparked my interest in trying to increase awareness and decided to give it a try."

Then he met Chad Bauer, BCAN Omaha Chapter vice president. Over that next year, Jeff learned about the different things he and the Chapter could do. Jeff focused on training to become a speaker about bladder cancer. He attended the BCAN 2016 Bladder Cancer Think Tank in Denver, where he learned about the latest research for diagnosis and treatments to improve lives for bladder cancer patients.

If having a 3-year-old and twin one-year-old children wasn't enough to keep this Dad busy, Jeff notes, "we've done two walks as an official chapter. We recently had our first spaghetti fundraiser auction for BCAN. We raised \$3,000 and about 100 people came out for spaghetti. That was a great success for us



and we are looking at what we do to make it better next year. This year, before our 2017 Walk, we will be a community-sponsored organization at an Omaha Storm Chasers game (they are the local affiliate of the

Kansas City Royals baseball team) and we hope to get additional excitement and exposure for AmpUp! We also want to get the media more involved in what we're doing."

"Now that we're a BCAN Chapter, we ensure that all of our events are on social media by posting updates on what we're doing, and how the events have gone. We use social media to let people know we're having success, to thank our sponsors and to let them know their donations went to a good cause."

An avid tweeter, Jeff likes to share unique and inspiring stories, as well as BCAN posts about bladder cancer. "We try to share those as much as possible on Twitter and Facebook to make sure we're maximizing the impact of our messages. We want it to become a 'thing that the news media can't ignore' and hope to get them to publish articles, as well as stories about bladder cancer."

When asked what advice he would share to help others raise awareness Jeff had some specific ideas. "I think one of the biggest things we can do is to set up a walk - even if it's small, that's okay.



**One thing I've learned is that if one of those people you tell about the walk didn't know about bladder cancer previously... now that person knows, and can tell other people about the signs and symptoms."**

Attending local health fairs is another way that Jeff and the Omaha Chapter raised awareness last year. "You can get a booth and tell people about bladder cancer. (Contact BCAN if you plan to participate in a health fair in your community and we can send you information to hand out!) Learn what resources the urologists and oncologists in your local area have, such as local support groups. People can also reach out to their doctors to let them know that BCAN has free materials they can give to their patients. Bladder cancer survivors can make sure no one else has the 'Hey, I had no clue about any of that when I was diagnosed' experience. Finding someone who's gone through it can help somebody get through those first weeks and months." (Contact BCAN's Survivor 2 Survivor program)

*Thank you for all you do for BCAN Jeff!*



#### Diane's story continued from Page 3

For the first time in 30 years, we have new immunotherapy treatments approved and additional promising new treatments on the horizon. BCAN's research program attracts the "best and the brightest" to focus on improving outcomes for bladder cancer patients. BCAN's resources and services support patients across the bladder cancer spectrum.

The work of BCAN has been a very personal mission for me and my family. John's strength, courage and love are an essential part of everything we do. It's this love that inspires me and motivates me to continue to work hard to make a difference in the lives of all who are impacted by bladder cancer.

To read more of Diane and Jeff's stories, visit [www.bcan.org/bladder-cancer-story/](http://www.bcan.org/bladder-cancer-story/)

## Young Adults with Bladder Cancer: “Why Me? It’s not supposed to be me...”



Sam Chang, MD

**Dr.** Sam S. Chang, M.B.A., Professor of Urologic Surgery at Vanderbilt-Ingram Cancer Center, knows a bladder cancer diagnosis is difficult at any age. However, bladder cancer is much rarer in twenty or thirty-year-olds. “Younger folks question ‘why me?’ With many younger patients, there may be something going on earlier in the genetic and mutation cycle, especially if they have not been exposed to any known risk factors such as smoking,” he noted.

Most younger patients have non-invasive disease. They receive intravesical therapies or conventional TURBTs, and they seem to respond. Some have more aggressive disease and require cystectomy, chemotherapy, or combination treatments. “You take into account all the things that can ultimately affect any patients with the procedures to treat bladder cancer. But treating younger patients is compounded by issues regarding fertility, sexual activity, and even body consciousness that tends to become more of an issue with younger male and female patients” according to Dr. Chang.

**“The vast majority of younger patients become quite proactive. They want to live another 50 or 60 years. They embrace the notion ‘I’ve got to be on top of things and try to live a healthier lifestyle.’”**

“I’ve had patients in their teens with this diagnosis. Some do become depressed. They say, ‘Why care?’ They may become less engaged in their physical, social or psychological well-being. I am not as good with handling that situation. I bring in counselors, psychiatrists and psychologists to help because these patients clearly have the burden of the disease in addition to having it at such a young age.” Dr. Chang went on to explain, “Even younger physicians may not be as well equipped or experienced with an understanding that there are so many issues beyond the physical well-being of care that affect these patients.

I’ve had a few of these younger patients over the years. Most of them, honestly, once they get the diagnosis, handle it well. Those that don’t, what are we going to do? You start making calls. You start finding individuals who can offer help and support, such as BCAN’s Survivor 2 Survivor volunteers.”



In 2015, the U.S. Senate declared May as National Bladder Cancer Awareness Month. Whether this is good news or bad news depends on which side of a bladder cancer diagnosis you fall. The numbers of survivors keeps growing. In recent estimates, there are over 574,250 patients with that diagnosis. That number is expected to jump to 754,280 in just ten years. BCAN wants to be there for those who learn about bladder cancer for the first time this year. We are here for the warriors fighting the disease and the community of bladder cancer survivors. We have a wealth of information developed and reviewed by medical experts to inform and encourage patients to be partners on their health care team.

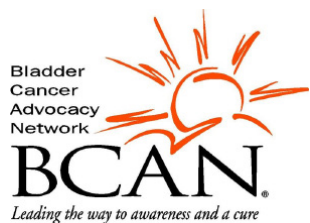
Across the country BCAN Chapters, medical centers and individual patients can help raise awareness of the fifth most common cancer in the US. BCAN volunteer Marge, has already started her Bladder Cancer Awareness Month efforts in her home state. “Awareness and education is much needed across the State of PA, both in urban areas and underserved communities. The lack of awareness of the prevalence of bladder cancer continues to be a deterrent to early detection and treatment. It is for this reason that I again seek the passing of a Resolution in the State of PA designating May as bladder cancer awareness month. As the capital building cloaks itself in orange, we hope that this will inspire conversations about bladder cancer and its many signs and symptoms.”

Check out some of the things that have been done in the past and let us know what you plan to do to let others know about BCAN and bladder cancer this May!



BCAN patient advocates  
on Hill Day 2015

Visit [www.bcan.org/home/bladder-cancer-awareness-month/](http://www.bcan.org/home/bladder-cancer-awareness-month/) to see photos and learn more! Share on social media!



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**BCAN**  
Survivor2Survivor

Connecting bladder cancer patients and caregivers with volunteer survivors who can provide their firsthand account of life with a bladder cancer diagnosis.

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CONNECTED?

DO YOU WANT TO BE A  
VOLUNTEER?

Contact us:



(301) 215-9099 x 212



[survivor@bcan.org](mailto:survivor@bcan.org)