

THE BEACON

Connecting the Bladder Cancer Community

Spring 2015

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Reflecting on 10 Years of Advocacy

It's hard to believe it has been 10 years since my late husband John and I started BCAN. We had a simple idea: something needed to be done to raise awareness about bladder cancer and improve the lives of the thousands of people impacted by the disease. We didn't have a "grand plan" at the time, nor any expectation of what we might be able to accomplish. But from the beginning, we were able to tap into the energy and commitment of others all around the country who wanted better information, increased support, and improved treatments for bladder cancer patients. We all started talking about bladder cancer and I am humbled and amazed at what we've been able to accomplish together.

We started talking with urologists, medical oncologists and other medical professionals who treat the disease, and who were committed to improving outcomes for their patients. After our first meeting at a medical conference in May 2005, we had a Scientific Advisory Board of 18 specialists, representing major medical institutions all around the country. Our partnership with the medical community has been an essential element in BCAN's ability to provide educational support for patients and their families, and has been invaluable in developing and supporting BCAN's research program.

We started talking to other survivors and family members through the Bladder Cancer Webcafe, which in 2005 was the only means of connecting with others around the country. We recruited volunteers to help us design and support our new website, and to help us raise awareness about bladder cancer in their own communities. Today our volunteer network spans the country, with walks and events raising the profile of bladder cancer, as well as raising much needed funds for BCAN's programs.

We started talking with friends and family, asking them to provide financial support to get BCAN underway. Our initial circle of supporters has now grown to over 35,000 people, many of whom have continued to donate to BCAN over many years.

Our partners, volunteers and donors are united by the common goal of improving the lives of those impacted by bladder cancer and creating a community of hope.

The first 10 years has been a remarkable start, but, of course, we still have much work to do. Together, we are leading the way to awareness and a cure.

Diane Zipursky Quale
President and Co-Founder

PS - We can't let this milestone year go by without a celebration! We hope you will join us November 5th in Washington, D.C. for a special reception. Details coming soon.

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

BCAN Through the Years



Drs. Mark Schoenberg, Adam Kibel, and Edward Messing at the 2007 Think Tank in Cape Cod, MA.



BCAN 1st Anniversary Celebration in June 2006. (L to R) Dwight Bush, Diane Quale, Bob Schieffer, Toni Bush, and John Quale.



Mary Ann Aregood has been hosting a walk on the Jersey Shore since the Walk for Bladder Cancer began in 2011.



Team BCAN competes in the Philadelphia Triathlon.



Inside Politics Panel in 2008. (L to R): David Gregory, David Brooks, Gwen Ifell, Diane Zipursky Quale and Bob Schieffer.



Participants gather for a group photo at the 2012 Think Tank in Stowe, VT.



DC walkers stop for a photo at the Lincoln Memorial in 2012.

Sia Daneshmand, MD of USC presents at the 2011 Patient Forum in Los Angeles. Over 150 patients and caregivers attended the educational event.



Janice Ashley Retires from the Board of Directors

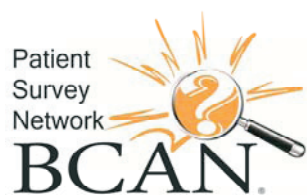


Janice Ashley announced her retirement from the BCAN Board of Directors in November. Jan is the President of the Ashley Family Foundation and devotes her time to several volunteer positions in the Rochester, NY area and spending time with her grandchildren. She has been a board member for BCAN since 2005, at the start of the organization, and was instrumental in directing the growth of the organization with a special interest in helping women with bladder cancer.

"The BCAN Board was transformative for me. Foremost, experiencing Diane Quale in her strong and productive leadership style as she formed BCAN was amazing! Secondly, the Board brought me from a mentality of never using the word cancer to openness. It was an opportunity to observe the dedication and commitment that the medical profession and other volunteers contributed to enhancing the lives of patients with bladder cancer. Thank you for the opportunity to serve."

Jan's leadership efforts helped BCAN to evolve and increase our community reach. We are grateful for her volunteerism and dedication to our mission.

Patient Survey Network Engages Patients in Research



We want to hear from you! The **Patient Survey Network** provides an opportunity for patients and caregivers to provide feedback and valuable insights that will direct future bladder cancer research initiatives.

The project, ***Engaging Patients in Bladder Cancer Research Prioritization***, is funded through a generous engagement award from the **Patient-Centered Outcomes Research Institute**. Our goal is to engage bladder cancer patients in the research process in a meaningful way ensuring patient and caregiver voices are heard.

Traditional research has relied on medical researchers and funding agencies to determine important research questions in bladder cancer. This project aims to turn this approach on its head – instead asking bladder cancer patients and caregivers about research questions that are important to them.

Once you join the survey network, we will send a survey with a few research questions identified as important by the scientific community. We will ask you to rank these research questions and also ask for any research questions that you also feel are important. We will use these responses to help identify and prioritize topics for future research. The survey will be available online and we can also provide a paper version.

We'd like to thank **Dr. Angela Smith**, Assistant Professor, Department of Urology, University of North Carolina and **Dr. John Gore**, Associate Professor, Department of Urology, University of Washington for leading this important project. To join the research network, go to www.bcan.org and click the Patient Survey Network icon or email psn@bcan.org.

BCAN Allocates \$500,000 for 2015 Research Awards

Advancing research is a core focus of BCAN's mission. Research programs are critical to improving diagnosis, treatment and quality of life for those impacted by bladder cancer.

BCAN's investment in research continues to grow. In December, BCAN announced the 2015 Bladder Cancer Research Innovation Award, generously supported by the **James Family Foundation** in conjunction with **Partner Fund Management**, for one award of \$300,000. Interest has been high for this award. Fifty-five letters of intent were submitted from experienced investigators and eight applicants were invited to submit a full proposal. The award winner will be announced in the summer.

Two Young Investigator Awards of \$100,000 each over two years will be granted this year. Through the generosity of BCAN donors, the eligible awards for 2015 are the **Miriam Gleberman Young Investigator Award** and the **Stephen Hale Gushée Young Investigator Award**. The Gushée award was funded by proceeds from the 2014 Palm Beach Shop & Stroll event. BCAN received 25 applications from 19 top academic and medical institutions across North America demonstrating growing interest in bladder cancer research.

To improve our impact in supporting research, BCAN became a member of the Health Research Alliance. The Alliance brings together over 60 not-for-profit, non-governmental funders of biomedical research and training to foster open communication and collaboration among members and address issues that are key to accelerating research discovery and translation.

For more information about BCAN's research program and currently funded projects, go to www.bcan.org/research.



The Patient Insight Webinar is an excellent resource for survivors and loved ones. This interactive education program explores bladder cancer in-depth. There are 22 webinars in the series. *Caring for the Cancer Caregiver* was recently added and featured an informative presentation by Allison J. Applebaum, PhD, Memorial Sloan-Kettering Cancer Center. Each installment features a live Q&A session. Go to www.bcan.org/webinars to view episodes.

The Walk for Bladder Cancer®:

Building Awareness and Funding a Cure Nationwide

The **Walk for Bladder Cancer®**, now in its 5th year, is BCAN's largest fundraising and awareness event. On Saturday, May 2nd, volunteers in nearly 60 cities in 30 states will host the event to honor survivors, remember those we've lost, and come together as a community to find a cure. From New Hampshire to Seattle, it is the dedication of Walk organizers, team captains, walkers, and donors that make the Walk a success.

This year's event features a new website with streamlined registration, fabulous fundraising incentives through the BCAN Blazer program, and special survivor recognition efforts. The Walk is expected to attract over 4,000 participants and raise \$600,000 to advance BCAN's education, support and research programs.



Sign Up Today!

Date: May 2, 2015*

**Dates may vary by location.*

Adults: \$20
Children 12 & Under: \$5

Register or Donate at
www.walkforbladdercancer.org

Thank You to Our Sponsor



Why I Walk

The **Walk for Bladder Cancer®** is more than a fitness and community event. Here's what motivates some of our supporters to walk. For more stories, check out our Facebook page every Friday at www.facebook.com/bladdercancer.



"I walk because of the tremendous support and love I receive from my family and friends, who honor my experience with bladder cancer by joining my team or spreading awareness. I walk to bring together those closest to me, to make connections, and to do something larger than myself. I walk because it feels rewarding to show the many blessings that have come through my cancer journey...and by putting that positivity out in the community, I hope to make it a little bit better."

Mary Beth Ballard, Bladder Cancer Survivor and Nashville Walk Organizer



"I walk for BCAN so others can share more smiles with their loved ones."

Calvin Hicks, Jr., pictured with his dad and bladder cancer survivor, Calvin Hicks, Sr., will join the DC walk on May 2nd.



"I walk for BCAN in honor of my "Grandad", Roy Forkey. He lost his life to bladder cancer after a four-year battle. I walk, not only to keep his memory alive, but also to promote awareness for this dreadful disease, in hopes that we can SAVE lives!"

Michele Goodnight
Walk Organizer, Oklahoma City

Survivors Speak Up about Radical Cystectomy



Behind the scenes at the Michigan video shoot in January.

In May, BCAN will launch a new video series, **“The New Normal: Living with a Urinary Diversion.”** This series includes eight video testimonials describing life following a radical cystectomy, more commonly known as bladder removal surgery.

The videos feature male and female survivors of different ages and lifestyles discussing their journey from diagnosis to living with their chosen diversion. The participants include patients with an ileal conduit, Indiana pouch, and neobladder.

“The most common call we receive at BCAN is from patients who are facing this life-changing surgery. They want to hear the first hand experiences of other survivors. We are pleased to offer this new on-demand resource,” said Monica Smith, Executive Director.

The videos are not intended to provide medical advice but rather, illustrate the day-to-day impact that surgery has on a survivor’s life. We hope the series will provide valuable information for those facing bladder removal.

We are grateful to **Abbott** for generously funding this project through an educational grant. We’d like to thank **Dr. Cheryl Lee, the University of Michigan, the Bladder Cancer Think Tank Survivorship Working Group, and Paige Erlich Productions.** Most important, thank you to the video participants for bravely sharing their experiences.

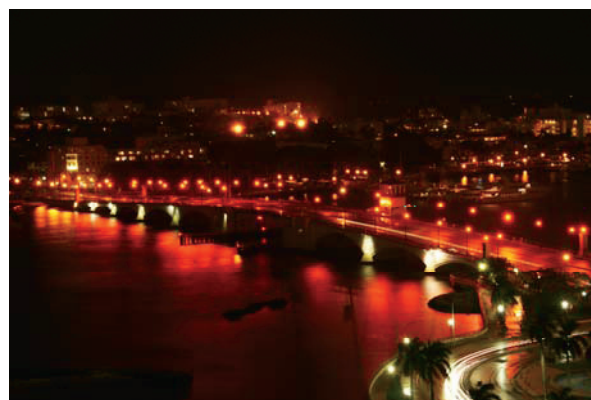
Shop & Stroll Turns Palm Beach Orange

Mary Gushée and the **Palm Beach Shop & Stroll committee** hosted the second annual event March 1 - March 7.

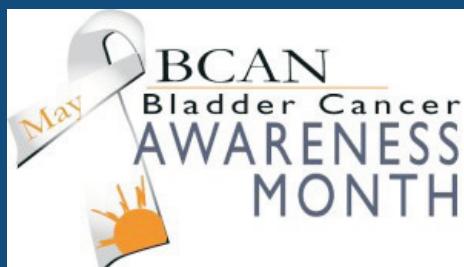
The event kicked off with a reception at the Mildred Hoit boutique. The week long event included more than 20 area shops and restaurants disseminating educational literature and supporting BCAN. **Hillie Mahoney** served as the event’s co-chair.

To date, the Shop & Stroll has raised \$50,000 to support bladder cancer research. Last year’s Shop & Stroll funded a Young Investigator Award in memory of Stephen Hale Gushée.

“We are grateful to Mary and the committee for their passion and dedication. I know their awareness efforts will help save lives,” said Diane Zipursky Quale, President and Co-Founder.



The Royal Park Bridge shines orange to promote bladder cancer awareness.



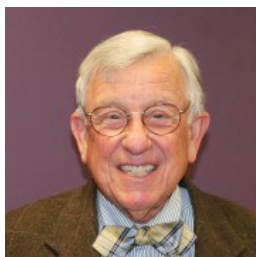
Mark your calendars - May is Bladder Cancer Awareness Month! Get involved by joining a walk in your area, contacting your representative to support bladder cancer research, and sharing information about bladder cancer signs and symptoms with your friends and loved ones. Follow our Facebook and Twitter pages throughout May for bladder cancer facts, advocacy alerts, survivor stories and more.

www.facebook.com/bladdercancer

Twitter @B_C_A_N

Ask a Doc: Bladder Preservation Therapy

Featuring Dr. William U. Shipley



William U. Shipley, MD, FACR is a Professor of Radiation Oncology at Harvard Medical School and Massachusetts General Hospital and BCAN Board Member.

What is bladder preservation therapy for bladder cancer patients?

Although the treatment offered by Urologists in the U.S. for patients presenting with muscle invasive bladder cancer is usually bladder removal, for many patients it is possible to treat these patients for cure using high-dose external beam radiation therapy in combination with chemotherapy while preserving normal bladder function. This treatment allows the patient to keep their bladder and still leaves the possibility of removing the bladder later if invasive tumors recur. Based on the results of clinical protocols carried out over the last 2-3 decades sponsored by the National Cancer Institute, optimal curative treatment requires close cooperation between the Urologist, the Radiation Oncologist and the Medical Oncologist who together will carry out this treatment. First, the Urologist must look into the bladder with a cystoscope and remove as much of the bladder tumor as is safely possible by doing a transurethral resection of the bladder tumor (TURBT). Then the Radiation and Medical Oncologists will work together to give the patient combined systemic chemotherapy (affects the whole body instead of intravesical chemotherapy that is put in the bladder), and external beam radiation over a 6-8 week period. This is an outpatient procedure where the patient only needs to come to the office or hospital for treatment. Chemotherapy and radiation are given together because the chemotherapy drugs make the tumor more sensitive to the radiation. Outcomes from randomized clinical trials have shown that this combination gives higher cure rates without adding significant side effects when compared to radiation therapy alone.

This “bladder sparing” chemo-radiation approach has another important element: It requires close follow up by the Urologist and the Oncologists. All patients must have regular cystoscopic evaluations to see if the cancer has returned. If the cancer recurs, the patient may need bladder removal or may require only intravesical chemotherapy for treatment of a new tumor on the surface of the bladder.

What should the patient know about this option?

Combined TURBT and concurrent chemo-radiation therapy is an aggressive curative treatment and requires motivation and commitment from the patient and often the family to undergo a 6-8 week treatment as an outpatient. It is usually well tolerated, even in the elderly, but there may be side effects which are most often temporary bladder or intestinal irritation. While bladder removal has long been the mainstay of therapy in this country for bladder cancer that invades the muscle the observation that many patients cannot tolerate the extensive surgery led to the development of alternative organ-sparing treatment approaches. There is now a substantial body of evidence with long term follow-up of patients treated with this approach to show that bladder preservation can be a good alternative to immediate bladder removal in well-selected and well-treated patients. Additional studies have reported that if this treatment does not eradicate the tumor or if a muscle invading tumor recurs, bladder removal can be carried out without significant increases in surgical complications compared to those seen in cystectomy patients without this treatment initially. These chemoradiation treatments are available in all major cancer centers, including over 90 centers in the U.S. and Canada.

Who is a good candidate for this treatment?

Many reported prospective studies from national clinical trials and from single institution experiences have shown that the patients that do particularly well with this treatment include those: with tumors that are able to undergo a visibly complete resection of the tumor, with tumors that are judged to be on clinical grounds invading only the muscle wall of the bladder but not deeper, with tumor presenting without obstruction of one ureter (called without hydronephrosis), and with tumors that, following an induction course of chemo-radiation, show a complete response when the tumor is re-biopsied usually after about 4 weeks of treatment. Additionally, most patients that are judged to be medically poor candidates for total bladder removal can often be well treated with chemoradiation.

Recently chemotherapy drugs, in addition to the initially recognized Cisplatin, that can assist effectively the radiation in eradicating the tumor in the bladder have been shown to include Mitomycin C, 5-FU, and Gemcitabine. These drugs are often better tolerated than Cisplatin, particularly in those patients with poor kidney or hearing function.

How can you find out if you are a good candidate for bladder preservation therapy?

Because many Urologists lack personal experience in carrying out this approach with a dedicated team of bladder specialists including Radiation and Medical Oncologists, it is best to have a consultation with a Radiation Oncologist in a community or academic cancer center. If patients are having difficulty identifying an appropriate local radiation specialist, they can contact BCAN who can put them in touch with me. Contraindications to this treatment would be patients who have had prior pelvic radiation therapy or who have medical conditions of the pelvis such as ulcerative colitis that would make radiation therapy potentially harmful.

Read more of our interview with Dr. Shipley including his comments on chemo techniques used in Japan and future of bladder preservation therapy at www.bcan.org/shipleyinterview.

Seeking Recruits for Volunteer Programs

As a grassroots organization, BCAN depends on volunteers to carry out all aspects of our mission. We are actively recruiting new volunteers as we continue to expand our outreach and awareness efforts.

The **BCAN Connection** program is an information and resource line for bladder cancer patients, caregivers and survivors. Staffed by volunteers across the country, this program offers practical help for those impacted by bladder cancer including financial information, educational resources, support referrals, and local medical centers.

Survivor 2 Survivor matches newly diagnosed patients with bladder cancer survivors, who share their particular experience and also let new patients know that they can continue to thrive after bladder cancer. This is a flexible volunteer opportunity with a minimal time commitment. Volunteers are matched based on diagnosis, treatment, and lifestyle.

The **Speaker's Bureau** raises awareness about bladder cancer through volunteers who give talks about the basics of bladder cancer or "Bladder Cancer 101" in their local community. The program focuses on three areas - sharing information at health fairs, sharing your personal story to make an impact, and conducting a formal educational presentation. BCAN will host a training session for this program in May.

To get involved contact Jeanne Mahoney, Community Resource Coordinator, at 1-888-901-2226 (BCAN) or via email at jmahoney@bcan.org.

A Snapshot of BCAN in the Community



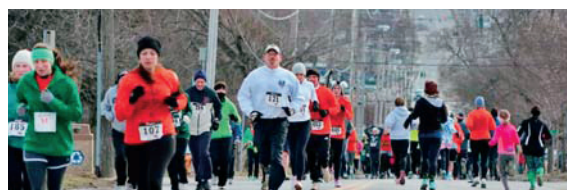
David Langham, President of the NC Triangle Chapter, presented at the Durham Rotary Club.



Vanderbilt-Ingram Cancer Center partnered with BCAN to host, "Living with Bladder Cancer." With over 150 attendees, this half-day educational event was an opportunity for patients, caregivers and family members to hear from medical experts as well as to network with others impacted by bladder cancer.



Virginia based volunteers Rick and Amanda Bulifant and Monica Austin-Cox and Matt Cox raised awareness at the CBS Healthy Lifestyle Expo in Richmond, VA.



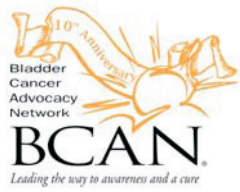
The 4th Annual Run for Dennis was held on March 14 in Oswego, NY. This event was held in memory of Dennis Pacheco and to support funding for bladder cancer research and treatment.



Thank you to Cindy Duffy and her family for organizing the Polar Bear Plunge again to kick off the New Year in Bloomington, Indiana. This year's theme was hippies!



The Albany Chapter leaders, Dr. Michael Perrotti (pictured above) and Dr. Duncan Savage presented the latest findings in bladder cancer during the medical grand rounds presentation at St. Peter's Hospital.



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STEP UP!

Walk for Cancer
Leading the way to a cure



Register Today!
www.walkforbladdercancer.org

May 2, 2015 *

* Dates may vary in some locations