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Shining the light on bladder cancer, the “elephant” in the room

BCAN Co-Founder Diane Zipursky Quale has been shining a light on and raising awareness about bladder cancer for more than twelve years. Those that know Diane have often heard her refer to the disease as the ‘elephant in the room.’ This year at the BCAN Bladder Cancer Think Tank, we took time to recognize Diane Zipursky Quale for her clear and unwavering dedication to the bladder cancer community. BCAN Board Chair, Gerald McNamara kicked off a special celebration by acknowledging “the great vision, determination, skill, and relentless optimism Diane has shown these past twelve years. She has built a great organization that has given so much hope and support to those whose lives have been touched by bladder cancer.” Gerry then invited four individuals to

speaking about Diane’s influence on our bladder cancer research community.

Though Diane’s husband John passed away from bladder cancer, he was very involved in the beginning of BCAN. John’s doctor, Mark Schoenberg, was the first to reflect on the early years of BCAN and the first Think Tank in 2006.

“Diane’s tremendous energy and commitment gave us a place to grow, to learn how to speak better to patients and each other about the disease, and to collaborate.”

Dr. Schoenberg toasted Diane to thank her for “making it possible for us to get together on an annual basis, for people to

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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...



In 2005, John and Diane Zipursky Quale, motivated by their bladder cancer personal experience, founded the Bladder Cancer Advocacy Network (BCAN). What started with a sheer determination to reach the masses to let them know that bladder cancer does exist and can be deadly, has evolved over the past twelve years into a seven chapter and more than 40,000 constituent's organization that has funded more than \$3,000,000 in bladder cancer research.

For more than a decade, Diane has refused to allow the bladder cancer discussion (the elephant in the room) to be side lined. This is evident through the twelve years of BCAN hosting our Think Tank, the only scientific and medical meeting dedicated to bladder cancer in the country.

BCAN has always been a hub for advocacy, education, and support for patients and critical research funding.

Diane's work in the bladder cancer space has attracted volunteers like our well known and much-beloved Pat Boumansour. In this newsletter, you will read about Pat's dedication to raising awareness through her husband, Mike, as he shares his story about Pat's recent passing.

Also in this fall newsletter are BCAN updates on our 2017 work. Look inside to find out more about Think Tank, our Walk to End Bladder Cancer, patient support programs, and the upcoming volunteer Leadership Summit.

BCAN is an organization that remains on the front lines in the fight against bladder cancer; we ask you to join us by getting involved.

- Read stories of other patients and caregivers touched by bladder cancer and share your personal story by going to www.bcan.org/my-bladder-cancer-stories/
- Support BCAN efforts by making a donation online. Visit www.bcan.org and select the donate button or enclosing a gift in the envelope attached to this newsletter

Finally, as I move into my second year at the Bladder Cancer Advocacy Network, I am honored to continue to work with the staff, Board of Directors, volunteers and (yes) Diane Zipursky Quale to create an environment where bladder cancer is the primary focus and will never again be considered the "elephant in the room."

Sincerely,

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

Andrea Maddox-Smith
BCAN Chief Executive Officer

Remember BCAN on
#GIVINGTUESDAY™
November 28, 2017



*"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

Continues on next page



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

Cheryl Lee, MD reflects on Pat Boumansour and bladder cancer metastasis



*I*t is a blow to think that someone like Pat, a woman I viewed as one of our greatest treatment successes, still succumbed to bladder cancer so many years after therapy. As a urologist, my primary area is not metastatic bladder cancer, but I certainly have some patients who develop metastases (disease that spreads from the bladder to other parts of the body). When you consider all bladder cancer patients, few (<5%) have metastases at the time of their diagnosis. But patients with muscle invading cancers have a significant risk of cancer spread during their life, despite definitive treatment with surgery or radiation.

As Pat has shared so often with the bladder cancer community, she was treated with radical cystectomy (bladder removal). She did well in her recovery period; she had a series of very good and high-performing years. Five-years after her surgery, there was no evidence of recurrence. Everyone was optimistic about her long term prognosis.

There are several important messages we can take away from Pat's experience,

- It is important to have cancer surveillance long-term, at least through 10 years after your treatment. Pat had regular follow up, but unfortunately her recurrence could not be detected earlier.
- We can't let cancer cripple our lives. Pat made it a point to spend her time living, growing, developing and empowering people. Although there is a risk of bladder cancer recurrence after any treatment, even down the line, we can't let that hamper our ability to live today. We should all plan and pursue the things that bring us enjoyment.
- As a survivor community we have to keep working to improve the everyday lives of bladder cancer patients. Pat was incredibly passionate about this point. She spent her time trying to build resiliency within the bladder cancer community.

She believed in the ability of the patient to help inform and improve his or her destiny. She always felt that survivors were key members of the treatment team, and they are!

- One final message that is a little trickier, but important nonetheless. As we enjoy freedom from the disease, we have to recognize that unexplained symptoms that arise may be important messages. We have to listen to our bodies and ask questions. As a doctor, I want to know about signs and symptoms that worry my patients.

It's always hard when patients ask me, "Am I cured?" I usually explain that most recurrences happen in the first two years after treatment. After that, being free of disease at 5 years from treatment is an important benchmark since the vast majority of people who are free of disease at this point will be cured. Ultimately, when someone has been free from disease ten years after treatment I feel quite comfortable saying, "You're cured." But, even after this period of time, those who have a urinary diversion still need periodic surveillance to monitor the health of their kidneys and their body salts.

In the end, Pat's death was difficult for so many of us. She was the epitome of treatment success. She was able to get back to her life, embracing her regular activities, her interests, and her many hobbies.

Pat's experience with bladder cancer empowered her to help others. Her life was a vibrant example that should continue to motivate and inspire our entire community.



Since 2006, the BCAN Think Tank has been the only meeting in North America dedicated to bladder cancer. The 2017 Bladder Cancer Think Tank in Charlotte, NC, was the largest to date with 223 attendees. This

meeting truly is an opportunity to “Collaborate to Move Research Forward.” Participants came from 30 states and four countries, representing more than 60 different academic and healthcare institutions. The Think Tank continues to grow steadily with increased diversity of patients and health professionals.

2017 Think Tank in Numbers

75 urologists

44 medical oncologists

29 sponsor representatives

25 patient advocates

24 researchers

4 nurses

3 pathologists

2 government researches

2 radiation oncologists

1 veterinary oncologist

1 social scientist

1 epidemiologist



Timothy Gilligan, MD

Dr. Timothy Gilligan from the Cleveland Clinic delivered an inspiring keynote address, “Using Communication Skills to Transform Healthcare, Our Organizations and Ourselves.”

General panels presented on Patient Centered Approaches to Research, Sequencing and Tissue Based Biomarkers, and concluded with a panel addressing Future Targets and Therapeutic Approaches – Beyond Immunotherapy.



Cory Abate-Shen, PhD

The BCAN 2015 Bladder Cancer Research Innovations Award winner, Cory Abate-Shen, PhD, and 2015 Young Investigator Awardee Philip Palmbo, MD, PhD, recapped two years of research supported by BCAN. In addition, we had presentations from our first one-year Young Investigator Awardees (2016) Niannian (Eve) Ji, PhD, and Kent Mouw, MD, PhD, along with our four John Quale Travel Fellows.



Patient advocate, Neil Kurtz, received the unofficial “best dressed” award



Breakout sessions on Friday and Saturday encouraged in-depth collaborative discussion on 16 different topics. These included communication, bladder preservation, remote monitoring of bladder cancer patients, and survivorship issues. Breakouts also focused on: maximizing mouse models for translational immunotherapy, upper tract disease issues, sexuality after bladder cancer, patient centered outcomes research, novel immunotherapy combinations to treat bladder cancer, precision

medicine and unmet educational and psychosocial needs across the bladder cancer continuum, novel therapies for non-muscle invasive bladder cancer, and strategies for optimizing radical cystectomy outcomes. Clinician researchers discussed tough cases related to radical cystectomy and management of toxicity related to immunotherapy. The translational scientists focused their discussion on opportunities and future directions for upper tract disease research.



To read more and see photos from the 2017 Think Tank, visit www.bcan.org/2017-bladder-cancer-think-tank/

Thank you to all of our sponsors:

AstraZeneca, Bristol-Myers Squibb, Clovis Oncology, EMD Serono/Pfizer, Genentech, Incyte, Janssen, Merck, Spectrum, Taris
Eleven Bio, Ferring, Pacific Edge, Photocure, Abbott, Eli Lilly, Urogen

**If it's between Uncle Sam
and the Bladder Cancer
Advocacy Network, guess
where my IRA will go?**

*(You can bet your bottom
dollar it'll go to BCAN!)*



Gifts Anyone Can Make Through an IRA

Did you know that when you designate retirement plan assets to your heirs, taxes can slice away as much as a third of your estate before your loved ones see a penny? But if you make the Bladder Cancer Advocacy Network the beneficiary of your retirement plan, the assets go to BCAN—tax-free!

Consider leaving other, less tax-burdened assets to your heirs and leave your IRA to the Bladder Cancer Advocacy Network. It benefits your loved ones, BCAN, and the greater bladder cancer community—a win-win-win!

- ▶ Your loved ones receive more from your remaining estate.
- ▶ BCAN receives a gift to educate and support bladder cancer patients, survivors and caregivers for generations to come.
- ▶ The needs of the greater bladder cancer community can be sustained for the long-term.



Bladder Cancer Advocacy Network
4915 St. Elmo Avenue, Suite 202
Bethesda, MD 20814

Interested?

Call us to learn more about how to
use your retirement assets to make a
transformational gift.

Anita Parker

Director of Development

301-215-9099 ext. 202

aparker@bcan.org

bcan.plannedgiving.org

Use Your Traditional IRA to Make Your Charitable Gift to BCAN

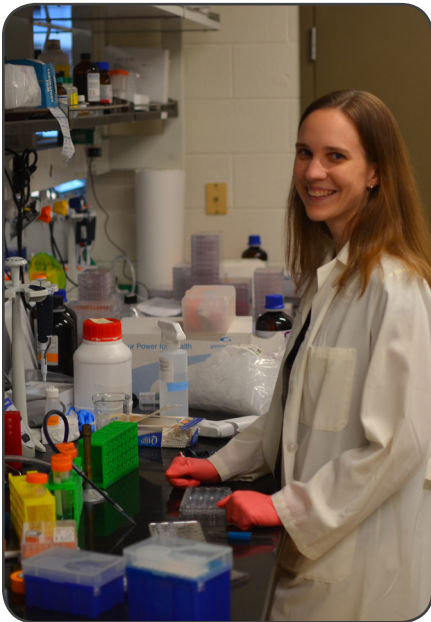
The IRA Charitable Rollover provides you with an excellent opportunity to make a gift during your lifetime from an asset that would be subject to multiple levels of taxation if it remained in your taxable estate.

H.R. 2029, the Protecting Americans from Tax Hikes Act of 2015 permanently extended the IRA Charitable Rollover. Originally passed in 2006 as part of the Pension Protection Act, the IRA Charitable Rollover allows individuals age 70½ and older to make direct transfers totaling up to \$100,000 per year to 501(c)(3) charities, without having to count the transfers as income for federal income tax purposes.

Questions	Answers
1. Who qualifies?	Individuals who are age 70½ or older at the time of the contribution (you have to wait until 6 months after your 70th birthday to make the transfer).
2. How much can I transfer?	Up to \$100,000 per year. The provision no longer has an expiration date.
3. From what accounts can I make transfers?	Transfers must come from your IRAs directly to BCAN. If you have retirement assets in a 401k, 403b etc., you must first roll those funds into an IRA, and then you can direct the IRA administrator to transfer the funds from the IRA directly to BCAN.
4. To what charities can I make gifts?	Tax exempt organizations that are classified as 501(c)(3) charities, including BCAN, to which deductible contributions can be made.
5. Can I use the IRA Charitable Rollover to fund life-income gifts (charitable gift annuities, charitable remainder trusts, or pooled income funds), donor advised funds or supporting organizations?	No, these are not eligible.
6. How will BCAN count the gift?	We will give you full credit for the entire gift amount.
7. What are the tax implications to me?	<ul style="list-style-type: none"> Federal — You do not recognize the transfer to the Bladder Cancer Advocacy Network as income, provided it goes directly from the IRA administrator to us; therefore, you are not entitled to an income tax charitable deduction for your gift. State — Each state has different laws, so you will need to consult with your own advisors. Some states have a state income tax and will include this transfer as income. Within those states, some will allow for a state income tax charitable deduction and others will not. Other states base their state income tax on the federal income or federal tax paid. Still other states have no income tax at all.
8. Does this transfer qualify as my required minimum distribution?	Once you reach age 70½, you are required to take required minimum distributions from your retirement plans each year, according to a federal formula. IRA Charitable Rollovers count towards your minimum required distribution from the IRA for the year.
9. Can my spouse also make an IRA Charitable Rollover, even if we are married and file jointly?	Yes, every individual can use the IRA Charitable Rollover for up to \$100,000 each year.
10. How do I know if an IRA Charitable Rollover is right for me?	<p>You are at least age 70½, and:</p> <ul style="list-style-type: none"> You do not need the additional income necessitated by your minimum required distribution, OR Your charitable gifts already equal 50% of your adjusted gross income, so you do not benefit from an income tax charitable deduction for additional gifts, OR You do not itemize deductions, OR You are subject to income phase-outs on your income tax deductions.
11. What is the procedure to execute an IRA Charitable Rollover?	We offer a sample letter you can send to your plan provider to initiate a rollover. Make sure that you contact us when you direct the rollover so we can look for the check from your IRA administrator.

Your Research Dollars at Work in 2017

BCAN is committed to supporting bladder cancer research. “Since we began our Young Investigator Awards, BCAN has invested more than one million dollars to support early career researchers. Advancing quality research has always been a top priority for BCAN. Funding their work exemplifies our efforts to make a difference in the lives of those diagnosed with bladder cancer.” – Andrea Maddox-Smith, Chief Executive Officer of BCAN. This year, your support helped BCAN fund two one year Young Investigator Awards.



The Stephen Hale Gushée Young Investigator Award will support the research of Tracy Rose, MD, MPH, Assistant Professor at University of North Carolina Chapel Hill, for her research, “Defining the Immune Response to Chemotherapy and Chemo-Immunotherapy in Muscle-Invasive Bladder Cancer.” Newly approved immunotherapy treatments are showing great promise for many bladder cancer patients. Yet the complicated immune system changes seen with standard chemotherapy and chemotherapy in combination with immunotherapy have not been studied in bladder cancer. Dr. Rose’s work will assist the development and optimization of chemo-immunotherapy combinations in bladder cancer to ultimately improve the cure rate of this deadly disease.

“This award is an incredible honor that will allow me to advance our understanding of the immune response to chemotherapy and chemo-immunotherapy in patients with bladder cancer, and will help me develop skills that are so valuable to an early career researcher like myself.”

– Tracy Rose, MD, MPH

The JPB Foundation Young Investigator Award will further the research of Byron Lee, MD, PhD, Assistant Professor at the Cleveland Clinic Foundation, on “Ascertaining the Role of Mutations in COMPASS-like Complex Members in the Development of Upper Tract Urothelial Carcinoma.” Upper tract urothelial carcinoma (UTUC) accounts for 5-10% of all urothelial carcinomas. Very few treatment options exist, especially for those patients who have disease recurrence after kidney removal and inadequate kidney function for cisplatin-based chemotherapy. Dr. Lee will be investigating how mutations affect disease progression and response to therapy. His goal is to deepen the understanding of how UTUC arises and also to provide novel drug targets for testing.

“I am deeply honored by being selected for this award. My research focuses on investigating the effects of COMPASS-like complex member mutations in the development of upper tract urothelial carcinoma. These mutations occur frequently; and currently, there are not much published data that shed light on their role in disease initiation, progression, and response to therapy. This will jumpstart my research in this area. I hope that my findings will provide a deeper understanding of chromatin modifier biology and ultimately benefit those who have urothelial carcinoma. I also look forward to the opportunity to share my work and build lasting collaborations with the bladder cancer scientific community.”

– Byron Lee, MD, PhD





The aim of the 2017 Bladder Cancer Research Innovation Award is to support exceptionally novel and creative projects with great potential to produce breakthroughs in the management of bladder cancer. BCAN is pleased to announce the 2017 Bladder Cancer Research Innovation Award was granted to Seth P. Lerner, MD. His study "Proteogenomic characterization of muscle-invasive bladder cancer to identify mechanisms of resistance and targets for therapy," will run for two years at Baylor College of Medicine.

"BCAN is excited to support the work of Dr. Lerner and his collaborators, to fill a much-needed research gap by focusing on patients whose muscle-invasive bladder cancer is resistant to the standard chemotherapy," notes Andrea Maddox-Smith, BCAN CEO. "Understanding genomic and proteomic properties of bladder tumors can inform innovative ways to identify specific targeted therapies to overcome chemotherapy resistance. This exceptionally novel and creative research project has great potential to produce breakthroughs in the management of bladder cancer."

"There is a large gap in our therapeutic armamentarium for patients who either cannot receive cisplatin-based chemotherapy or for whom chemotherapy is ineffective. Our team at Baylor is very excited to begin the work supported by this Innovation award that incorporates proteomic profiling to help us better understand mechanisms of chemotherapy resistance and to apply this in novel PDX pre-clinical models to test alternative therapeutic strategies."

- Seth Lerner, MD

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.

Thank you.

BCAN is a 501(c)3 organization. Your tax deductible donations can be made online or by check made payable to

Bladder Cancer Advocacy Network

4915 St. Elmo Ave, Suite 202 Bethesda, MD 20814



My Bladder Cancer Story

"Everyone has a story"

This year, over 79,000 people will be diagnosed with bladder cancer and even more are indirectly impacted by the disease. BCAN is well aware that there are real people behind those numbers.

BCAN's My Bladder Cancer Story Campaign is highlighting the stories of those impacted by bladder cancer in an effort to raise awareness and eventually find a cure. Share your story at www.bcan.org/my-bladder-cancer-stories/



Gerald McNamara and Diane Quale

get research funded, and for people to grow their careers in this bladder cancer space.”

Next, a 2009 John Quale Travel Fellow and a 2017 Think Tank

Steering Committee member, David DeGraff eagerly shared,

“Diane has made significant strides in improving the research environment for bladder cancer... and making the transdisciplinary way we all work together really function.”

David recalled, “When I got the 2013 Young Investigator Award, Diane called me personally to tell me. It seems like a small gesture, to call someone to tell them, but it’s not. It speaks to her commitment to the trainees that are coming up in this field. Her dedication to making sure scientists, translational researchers, and physician scientists have a strong voice in this bladder cancer community is important. It is difficult being a basic scientist today. Not every research community thinks about research the way we do... Diane has helped break down the barriers and helped us communicate in ways where we think about how we are the same and how we can work together.”

Next, BCAN patient and research advocate Rick Bangs came to the podium. In his remarks, he referenced the song “Who Tells Your Story” from the soundtrack of Hamilton. Rick spoke of Diane’s legacy being, “defined by not only what you do, but by the people who tell your story.” He went on to list values Diane has instilled in both BCAN and the Think Tank meeting. These values include the notion that “from the beginning, Diane has recognized the need to engage stakeholders that have been under-represented in the past: caregivers, radiation oncologists, social scientists, health economists, etc. - and that the science must be comprehensive, spanning the quality and quantity of life.” Rick continued, “We seek the cure(s) but recognize the pragmatic reality of our situation and the

value of translation science to propel us forward. This is a marathon, slow and steady wins the race, but we get in the starting blocks early.” Rick concluded his tribute by saying,

“Diane has forever changed our collective trajectory with the work she has done and enabled us to do, tossing a giant boulder into the once stagnant waters of bladder cancer research.”

Finally, medical social worker and 2017 Think Tank steering committee member, Heather Goltz, shared her social science and patient voice perspective on Diane’s influence in her life. Heather reflected on her grandmother who had been diagnosed with bladder cancer. A short time later, she met Diane as a John Quale Travel Fellow at the 2010 Think Tank. Heather shared the story of her first academic interview, when her presentation to faculty was on the formalization of BCAN as a nationwide advocacy organization. The good news is that, not only did she get the job, but Heather credits Diane and the Think Tank for nurturing her passion and launching her career in the field of bladder cancer research as a social scientist.




David DeGraff, Diane Quale, Rick Bangs and Heather Goltz

Thank you, Diane!

It is clear that you have been the driving force behind the successes of both BCAN and the Think Tank.

What's New @ BCAN?

Many faces.
Many questions.



Get the answers
about the 5th most
common cancer.

Get a free bladder cancer handbook at www.BCAN.org

Bladder Cancer Advocacy Network

Bladder Cancer Basics

For the Newly Diagnosed

Do you have your copy
of the newly updated
Bladder Cancer Basics?
Go online or call us
to request your free
copy now

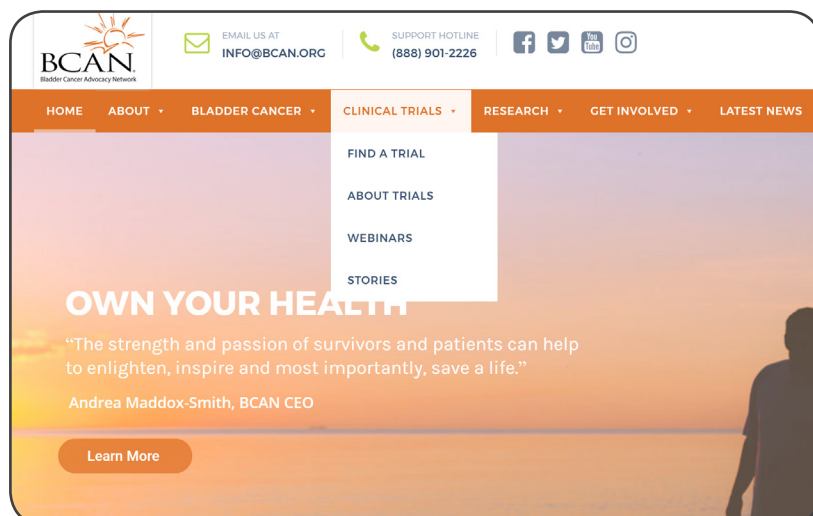
1-888-901-BCAN

También disponible en Español

Check out our new website and Clinical Trials Dashboard!

BCAN wants to ensure patients have the most up-to-date information on bladder cancer clinical trials.

Visit www.BCAN.org to find a trial. You can search by disease type and in multiple states. Log in and save the trials you are interested in. Get quarterly notification of new trials that start recruiting patients. Email them to your loved ones or even to your doctor!



Easier to search! Easier to read! Easier to share!

Dear Bladder Cancer Community - You are not alone.

A bladder cancer diagnosis can be scary. Whether you are a patient or someone who cares about one, it is easy to feel like no one understands what you are going through. But you are part of our community and BCAN has a wonderful network of volunteers who can help you navigate the challenges of learning about your disease.

The **BCAN Connection** is an information and referral line staffed fully by BCAN volunteers. Connection volunteers provide practical information and resources to assist bladder cancer patients and their loved ones.

To access the program, call

1-888-901-2226 (BCAN) ext. 207

Whether you are a patient or caregiver, the **Survivor 2 Survivor** program connects patients or their 'co-survivor caregivers' with a survivor volunteer who has undergone similar treatment. The volunteer survivors provide their firsthand account of life with a bladder cancer diagnosis.

To access the program, call

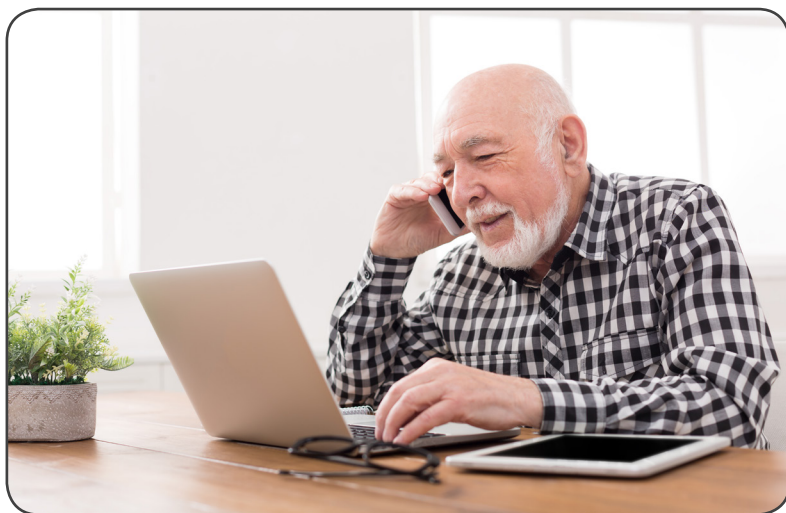
1-888-901-2226 (BCAN) ext. 212

Interested in volunteering?

Email **volunteer@bcan.org**
for more information.



New volunteer trainings
coming soon!



BCAN receives 2-year PCORI Award

BCAN is proud to have received our second two-year Patient-Centered Outcomes Research Institute (PCORI) Award to establish the Patient Empowerment through Engagement Research Training (PEER). The goal of this PEER training is to arm a group of bladder cancer patients and caregivers with an expertise in research to participate in the development of new bladder cancer research initiatives and clinical trials. By integrating patients, caregivers, and members of the healthcare and research communities, we hope to encourage a greater emphasis on strengthening partnerships to develop and implement Patient Centered Outcomes Research projects. Dr. Angela Smith of the University of North Carolina is the principal investigator in this award with co-investigator John Gore of the University of Washington. If you are interested in getting involved to share your 'lived experience' with bladder cancer to contribute to new research designs, contact BCAN at info@bcan.org or call **888-901-BCAN**.

PCORI's mission is to help patients and their medical teams make informed health care decisions. By providing high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care community, PCORI aims to improve patients' health care plan outcomes. Our first PCORI award in 2015 established the Patient Survey Network with over 1,500 patients and caregivers providing their perspective on important bladder cancer research.

\$580,000
in funds raised

Thank you to all who participated in the 2017



events across the country!

31
communities

250
teams



2,850
participants

Top Teams
Reynolds Strong
Brave for Dave
Pam's Peeps



BCAN WALK TO END BLADDER CANCER

Registration begins in October.

www.bcanwalk.org

Join us to learn about the role and impact of clinical trials in the advancement of bladder cancer treatment and new drug development. Find out what's on the bladder cancer research horizon. Get tips on the best practices to raise awareness of bladder cancer in your community. Hear about how you can make your voice heard in key bladder cancer legislative issues for 2018 and beyond.

Learn more and register:

www.bcan.org/2017-Leadership-Summit/



Inspiring Excellence in the Bladder Cancer Community

FRIDAY, OCTOBER 13 – SATURDAY, OCTOBER 14 | ROCKVILLE, MD



RESEARCH



ADVOCACY



EDUCATION

A two-day conference to educate, engage, and energize patient advocates.