

ANNUAL REPORT 2017

The mission of the Bladder Cancer Advocacy Network is to increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community.

2017 was an extraordinary year for the Bladder Cancer Advocacy Network (BCAN). We approached the year with renewed resilience and determination to remain the bladder cancer patient's go-to "hub" for advocacy, education and critical research funding.

In keeping pace with the fast changing bladder cancer ecosystem, we launched a newly designed website and Clinical Trials Dashboard with patient navigation and ease of use in mind. For the newly diagnosed, we modified the third edition of our signature piece, the Bladder Cancer Basics Handbook to include new treatments that were not available to patients when the last edition was published in 2006.

BCAN accomplished greater impact in research efforts this year. The 12th Annual Bladder Cancer Think Tank had record attendance with 225 clinicians, scientists, and patient advocates, all with a common goal of collaborating to move research forward. Also, the breadth and rigor of BCAN's awards process was considerable and resulted in two \$50,000 early career Young Investigator Awards and one (two-year) \$300,000 Innovation Award for a more experienced investigator.

Despite the many successes in 2017, we did not achieve everything we set out to do. We know that 70% of all bladder cancer patients are seen by community urologists. Unfortunately, the number of community urologists working directly with BCAN did not grow at the rate anticipated. However, engaging community urologists remains a high priority for BCAN and we will continue to push for collaboration in order to get our many resources to bladder cancer patients.

Finally, we saw many accomplishments in 2017 and are forever grateful to our volunteers, donors, healthcare professionals, researchers and industry partners who work so hard and care so deeply about the fight against bladder cancer. We are eternally grateful for your commitment and dedication to a life free of bladder cancer.

Sincerely,

Andrea Maddox-Smith,

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Gerald McNamara, Board Chairman When my late husband, John Quale, and I started BCAN in 2005, we had no five or ten year strategic plan. We just knew that it was time for bladder cancer patients and their families to have a public voice, to be empowered to make informed medical decisions, to feel part of a community, and to have reasons to believe — not just to hope — that treatment options and life expectancies would improve.

As I look back at 2017, I am filled with pride for what our donors have helped us create, and the positive impact BCAN is having on peoples' lives every single day. We all recognize that with a cancer diagnosis, the initial disbelief and fright are often followed by a multitude of questions, then information overload, and a resulting sense of losing control. Thanks to our generous community, BCAN provides assistance through all these phases. Over the years, I have heard from so many patients and their families about how BCAN has provided them with the type of support they desperately needed. Information is power, and I know from experience that with that knowledge and power, bladder cancer patients can take an active role in their treatment decisions, ensuring the best possible outcomes.

Our quest to advance bladder cancer research has produced tremendous results. Our research grant program focuses on investing in people, ensuring that the best and brightest researchers and clinicians are improving our understanding of bladder cancer and finding better treatments. It's wonderful to see so many of our John Quale Travel Fellows, who became involved with BCAN during their medical residencies or fellowships, now taking leadership roles in bladder cancer clinical trials and scientific conferences, as well as publishing exciting research outcomes.

For me, one unexpected product of BCAN's success is the opportunity created for members of the bladder cancer community to enrich their own lives by giving back. BCAN's ability to serve grows each year, thanks to the generosity of our supporters. The success of BCAN's volunteer-led "Walk to End Bladder Cancer" events in cities all around the country demonstrates the power we have as those affected by bladder cancer to engage, raise our voices, and make a difference. Together, we've made a significant impact over a short 12 years — but, in fact, we are just getting started! I am excited about the possibilities the future holds.

Sincerely,

ing to see

Diane Zipursky Quale Co-Founder

research

ADVANCING BLADDER CANCER RESEARCH

THANK YOU TO THE SPONSORS WHO SUPPORTED THINK TANK 2017













































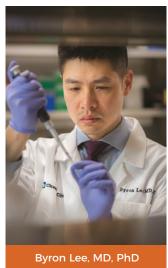


The 12th Annual Bladder Cancer Think Tank

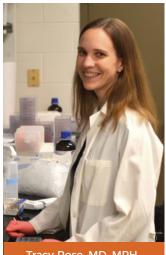
CHARLOTTE. NC

The 2017 Bladder Cancer Think Tank brought together 225 bladder cancer professionals, including urologists, medical oncologists, laboratory researchers, radiation oncologists, nurses, patient advocates, etc. What makes this gathering unique is each person's commitment to collaboration to move bladder cancer research forward.

The bladder cancer community honored BCAN's Founder, Diane Zipursky Quale, for her vision and dedication to everyone whose lives have been affected by bladder cancer over the past 12 years.







Tracy Rose, MD, MPH

2017 BCAN Research Awards

The 2017 Bladder Cancer Research Innovation Award was presented to: Seth Lerner, MD, FACS, Professor of Urology, Baylor College of Medicine. His research, "Proteogenomic characterization of muscle-invasive bladder cancer to identify mechanisms of resistance and targets for therapy" will run for two years.

This two-year award is given to support an experienced investigator whose exceptionally novel and creative project has great potential to produce a breakthrough in the management of bladder cancer.

The 2017 Stephen Hale Gushée Young Investigator Award was presented to: Tracy Rose, MD, MPH, UNC Chapel Hill. "Defining the Immune Response to Chemotherapy and Chemo-Immunotherapy in Muscle-Invasive Bladder Cancer"

The JPB Foundation Young Investigator Award was presented to: **Byron Lee**, MD, PhD, Cleveland Clinic Foundation. "Ascertaining the Role of Mutations in COMPASS-like Complex Members in the Development of Upper Tract Urothelial Carcinoma"

The Young Investigator Awards promote the development of early career researchers who are focused on bladder cancer.

With these 2017 grants, BCAN has invested \$3.9 million in bladder cancer research.



The 1st Annual New Discoveries Research Lecture and Luncheon

PALM BEACH, FL

This inaugural event was held at the Beach Club and featured Dr. David McConkey, Director of Johns Hopkins Greenberg Bladder Cancer Institute who spoke about promising new bladder cancer treatments. The purpose of this event was to educate the general public, to increase bladder cancer awareness and to raise funds toward a cure. Funds raised will be used to fund two Young Investigator Research Awards.

Patient Surveys

Patient surveys help companies gain an increased understanding of key issues related to bladder cancer diagnosis and treatment.

In 2017, over 500 bladder cancer patients helped steer companies to better understanding the impact of and desire for new treatment and diagnostic methods.

awareness & advocacy

INCREASING PUBLIC AWARENESS
ABOUT BLADDER CANCER RESEARCH

THANK YOU TO THE SPONSORS WHO SUPPORTED BCAN'S AWARENESS & ADVOCACY INITIATIVES IN 2017



















2017 AMP UP! Walk/Run to End Bladder Cancer

Since 2011, members of the bladder cancer community have come together to walk for healing and hope, in honor and memory of loved ones, and to increase awareness of the disease.

For 2017, BCAN hosted 31 walks (including two virtual walks), with 251 teams and 2,771 participants. Together, we raised \$576,605 toward the BCAN mission of education, advocacy, awareness and research.

Do It Yourself (DIY) Third Party Fundraising

In 2017, BCAN created a platform for individuals to support the organization and raise awareness by fundraising their own way. Thank you to those who created donation pages in honor or in memory of loved ones, held exercise challenges, golf tournaments and other events to benefit BCAN.







Volunteer Leadership Summit

ROCKVILLE. MD

This second annual, two-day conference engaged, educated and energized 95 bladder cancer survivors and BCAN volunteers, representing 20 states. In-person training was conducted and 44 Patient-Centered Outcomes Research Institute (PCORI) volunteers were trained in PEER (Patient Empowerment through Engagement Research).

Advocacy

BCAN's advocacy efforts are fundamental to our mission. BCAN participated in the following advocacy initiatives in 2017:

- Hill visits on behalf of patients to representatives along with our colleagues from the Rally for Medical Research and One Voice Against Cancer (OVAC)
- Hearings at the Food and Drug Administration as well as briefings on the Hill
- Meetings with key thought leaders at the National Cancer Institute
- Outreach to our constituents to support the Durbin-Blunt Amendment to include bladder cancer in the important Congressionally Directed Medical Research Program (CDMRP)

education

PROVIDING EDUCATIONAL AND SUPPORT SERVICES FOR THE BLADDER CANCER COMMUNITY

THANK YOU TO THE SPONSORS WHO SUPPORTED BCAN'S EDUCATION INITIATIVES IN 2017









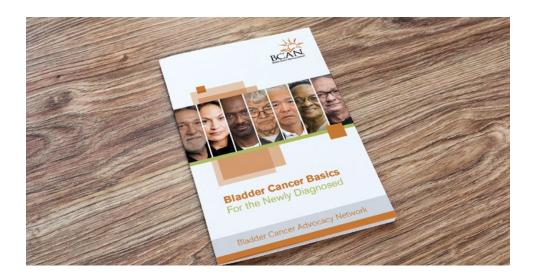












Bladder Cancer Basics For The Newly Diagnosed

With more than 250,000 copies in circulation, in 2017 this free resource was updated, translated into Spanish, and made available in print and online to individuals and medical offices nationwide.

This third edition includes the latest in diagnostics and treatment options, such as immunotherapy, and helps to empower patients by increasing their understanding of the risks, staging and treatment of bladder cancer.

Conversations: It's Time to Start Talking About Bladder Cancer

In 2017, BCAN introduced two new video Conversations from leading experts. Topics included:

- · Sexuality after Bladder Cancer
- Biomarkers

These conversations are available online to increase the understanding of key issues related to the development and implementation of significant topics concerning the diagnosis and treatment of bladder cancer.





Webinars

BCAN hosted 10 new webinars on the following important bladder cancer topics, and hundreds of participants were able to ask the experts questions during the live program.

- · How to be a Proactive Patient
- · The Toughest Conversation
- · Sexuality and Intimacy after Bladder Cancer
- · Life after Bladder Removal
- · Understanding Bladder Cancer Pathology
- Upper Tract Urothelial Carcinomas (UTUCS)
- Systemic Chemotherapy
- · Non Muscle Invasive Bladder Cancer
- · Immunotherapy and Bladder Cancer
- · Women and Bladder Cancer

Archived recordings and a written transcript create enduring resources for patients and their families.

These webinars had more than 23.000 views in 2017.

Website/Clinical Trials Dashboard

The most visible change made in 2017 was revitalizing and rebranding the bcan.org website for greater ease and access to all of its content.

BCAN also restructured the online Clinical Trials Dashboard, which accomplishes the following:

- allows patients, families, and clinicians to search for clinical trials by their disease state and within multiple state and geographic locations
- · uses plain language for study summaries to explain the goals of clinical trials as much as possible
- enhances accessibility for individuals to save trials, email trials to others, and receive notifications of new trials

"I've been part of BCAN from the beginning, the BCAN website I think should serve as a model for a lot of different cancers."

- Gary Steinberg, M.D., FACS, Chairperson of the Scientific Advisory Board

Patient Support Initiatives

In 2017:

- 10 BCAN Connection volunteers helped guide callers (newly diagnosed patients and caregivers) to BCAN resources.
- 40 Survivor 2 Survivor volunteers shared their bladder cancer treatment experience and walked alongside patients seeking to understand what to expect from upcoming treatments.
- Throughout the year, Speaker's Bureau volunteers represented BCAN at health fairs and other events, bringing information and awareness to their local communities.
- The Inspire Online Community grew to more than 30,000 members in 2017.
- Chapters consist of volunteers who represent BCAN in their respective communities and share the BCAN mission they are BCAN's "boots on the ground" representatives n the community and provide a support group atmosphere combined with a social component. A Chapter in Las Vegas was added in 2017.

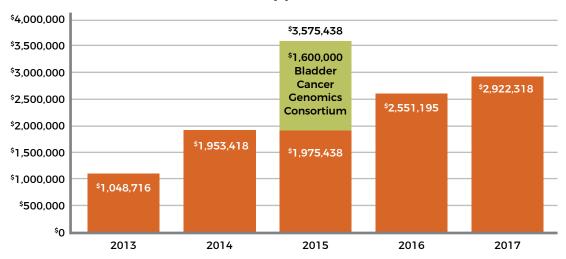
BCAN Chapters are located in: Albany, Corpus Christi, Dallas-Fort Worth, Greater Omaha, Pennsylvania, NC Triangle, New Jersey, and Las Vegas.

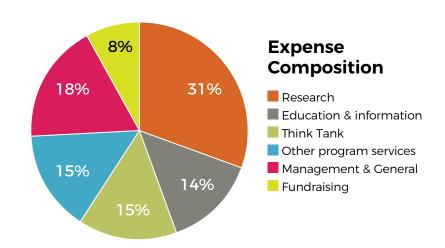
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volunteer leadership and staff

BCAN Public Support Revenue 2013-2017







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The following donors contributed \$500 or more to the Bladder Cancer Advocacy Network in 2017. Thank you for supporting our mission as together we are leading the way to awareness and a cure for bladder cancer.

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Roger Adams

William R. Adams

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Svana Thordardottir Agustsson

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"From the beginning, BCAN has always been focused on all of the survivors, not just the patient survivor, but also the caregivers, the partners, the family, and the friends."

- Rick Bangs, Patient Advocate





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