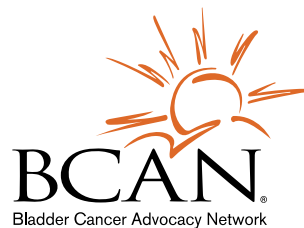
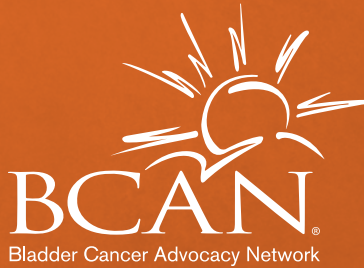




Giving Patients Hope

BCAN ANNUAL REPORT 2019





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.

OUR MISSION

*“Never underestimate the power of hope.
Hope fuels us with the energy and courage to go forward.”*

—Adele Basheer



A stylized black ink signature of Andrea Maddox-Smith.

Andrea Maddox-Smith
BCAN CEO



A stylized black ink signature of Gerald McNamara.

Gerald McNamara
Board Chairman

The Bladder Cancer Advocacy Network (BCAN) has been called a “beacon of hope” by many who learn about our programs and services in their quest for information once they receive a bladder cancer diagnosis. In this issue of our Annual Report, we will highlight some ways that BCAN gave hope in 2019 to those looking for answers about one of the most common cancers in America.

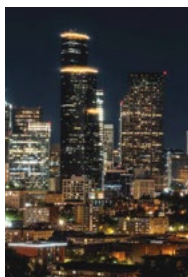
Last year, it was expected that more than 80,000 people would be diagnosed with bladder cancer and more than 17,000 people would not survive the disease. Throughout 2019, BCAN continued its critical mission of raising awareness about bladder cancer, including an advertising campaign to raise awareness during Bladder Cancer Awareness Month (May) and a special outreach to over 27,000 firehouses nationwide.

Donors enabled BCAN to fund \$450,000 in bladder cancer research in 2019, bringing our total investment to nearly \$5 million. New in 2019 was a research award for a Patient Centered Clinical Research Young Investigator, made possible by proceeds from the Palm Beach New Discoveries Research Lecture and Luncheon. The first award recipient's study will focus on financial toxicity experienced by bladder cancer patients.

Another highlight in 2019 was that, for the first time, our Think Tank scientific meeting was held in Washington, D.C. This new location enabled us to invite the Food and Drug Administration (FDA) to participate, including a FDA/CDER and BCAN workshop, and a panel review of the structure of the FDA Oncology Center of Excellence (OCE) and how expedited programs within the FDA strive to accelerate oncology drug development. Also, for the first time at the Think Tank, the John Quale Travel Fellows presented their research at a Poster Session.

BCAN's educational programs, support and information have given hope to patients, survivors and caregivers since 2005. New in 2019 was the Lunch & Learn Live programs which were held at seven locations throughout the country. These events provided a great way to have patients and their families learn from bladder cancer experts in their local communities, and to receive information about BCAN program offerings. One Lunch and Learn session resulted in the formation of a local support group.

Without the financial support of our donors, it wouldn't be possible to offer any of the programs included in this Annual Report. On behalf of bladder cancer patients, survivors, caregivers, volunteers, researchers, medical professionals as well as the BCAN Board of Directors and staff, thank you for giving hope for tomorrow.



Bladder Cancer Awareness

Although bladder cancer is one of the most common cancers in America, many are not aware of the risks or early signs. BCAN's Awareness initiative to increase understanding of bladder cancer was conducted through a yearlong multi-media campaign with an emphasis on Bladder Cancer Awareness Month (May). In 2019, BCAN joined our international counterparts by sharing key awareness messages, conducting bladder cancer awareness events, and arranging for buildings and landmarks to be illuminated in orange during May. The 2019 Bladder Cancer Awareness Campaign Activities reached out across various audiences, and included:

- Walk to End Bladder Cancer events in 25 US cities
- Creation and distribution of a Firefighter Awareness Poster to over 27,000 fire stations in the U.S.
- Print, digital and mobile ads nationwide
- Social campaign advertisements
- Creation and distribution of digital bladder cancer awareness videos
- Creation of PSAs for distribution to media outlets nationwide
- Building illuminations in various cities nationwide
- State, local and national proclamations for Bladder Cancer Awareness Month
- Coordinated communications campaigns with pharma partners to amplify awareness messages



Walks to End Bladder Cancer

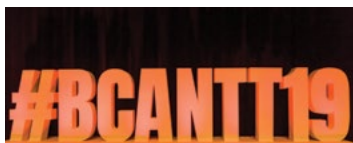
In April-June 2019, the Bladder Cancer Advocacy Network organized Walks to End Bladder Cancer in 25 cities across the United States, involving more than 3,500 enthusiastic participants and volunteers and raising more than \$650,000. BCAN's walks generate critical funds that enable us to offer educational resources and support programs free of charge, advance research, serve more patients and families, and continue as the leading provider of bladder cancer services and information in the US.

Top Teams for 2019

Brave for Dave (New York City)
 Pam's Peeps (Houston, TX)
 Rick's Highsteppers (Richmond, VA)
 Reynolds Strong (Long Island, NY)

Top Fundraisers for 2019

Dave Dimick (New York City)
 Rick Bulifant (Richmond, VA)
 Marge (Coffin) Tupper (Lehigh Valley, PA)
 Annie Gardiner (San Francisco, CA)



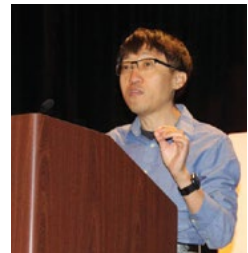
Left: Think Tank 2019 Program Co-Chairs, Sia Daneshmand and Matt Galsky. Below: Think Tank 2019 Program Steering Committee



Think Tank 2019

On August 8-10, 2019, BCAN hosted the premier bladder cancer scientific meeting of the year in North America, the 14th Annual Bladder Cancer Think Tank. More than 300 patients, advocates, doctors, researchers and other medical professionals gathered in Washington, DC to collaborate and advance bladder cancer research and advocacy. For the first time in Think Tank history, a workshop with the Food and Drug Administration (FDA) was included, entitled “Endpoints for the Development of Neoadjuvant Systemic Therapy Regimens for Muscle-Invasive

Bladder Cancer”. A diverse set of themes were covered throughout the meeting, including bladder cancer palliative care, immunotherapy, bladder cancer preservation, patient-driven endpoints and toxicity thresholds, regulatory science, genomic insights and biomarkers, computational biology and much more. Meeting attendees included leading urologists, oncologists, researchers, pathologists, social scientists, patient advocates and industry representatives, all whom are dedicated to improving the diagnosis and treatment and survivorship of bladder cancer.





New Discoveries Research Lecture and Luncheon

In 2019, the New Discoveries Research Lecture and Luncheon took place at the Beach Club in Palm Beach, Florida and featured a panel discussion on advances in bladder cancer research. The panel consisted of John L. Gore, MD, MS of the University of Washington School of Medicine, Seth P. Lerner, MD, FACS of the Baylor College of Medicine and Andrea Apolo,

MD of the National Cancer Institute. These renowned bladder cancer experts educated attendees as well as provided a glimpse into promising treatments used to combat one of the most commonly diagnosed cancers in the country. Proceeds from this event will be used to fund two BCAN Young Investigator Awards.

BCAN Bladder Cancer Research Innovation Award

In 2019, the members of the Bladder Cancer Research Network Management Committee evaluated 30 applications for the \$300,000 BCAN Innovation Research Award which supports experienced investigators who focus on exceptionally novel and creative projects that break new ground in the field of bladder cancer. Results from these bladder cancer research programs have been published in high-impact, scientific journals and have led to multi-institutional research collaborations funded by the National Cancer Institute.

The 2019 Innovation Award recipient was Philip Beachy, Ph.D., Professor of Urology and of Developmental Biology at the Stanford University School of Medicine. His research project addresses the need for better treatments for recurrent bladder cancer CIS (carcinoma in-situ) and intermediate and high-risk non-muscle invasive bladder cancer (NMIBC).



Philip Beachy, Ph.D., Professor of Urology and of Developmental Biology at the Stanford University School of Medicine

"The recognition that I received from this award undoubtedly played an important part in cementing my role in the international bladder cancer research community and fostered my success in securing external grant funding for my bladder cancer projects."

—Randy Sweis, MD, 2015 John Quale Fellow

"The BCAN YIA directly allowed me to pursue a project that I would not have otherwise been able to pursue and has served as a foundation for several additional grants and collaborations that will allow me to continue my research in bladder cancer."

— Kent Mouw, MD, PhD, 2016 Stephen Hale Gushée Young Investigator Award



Dr. Neelam Mukherjee



Dr. Sarah Psutka



Dr. Sumeet Bhanvadia

BCAN Young Investigator Awards - The BCAN Young Investigator Awards, (YIA) funded at \$50,000 each for one year, support the development of outstanding early-career research scientists and clinical cancer research investigators who have demonstrated a commitment to improve the understanding and treatment of bladder cancer. In 2019, three were selected to receive the YIA from a total pool of 24 applicants, and one was selected to receive the first Patient Centered Clinical Young Investigator Award.

2019 New Discoveries Research Young Investigator Awardees:

Dr. Neelam Mukherjee, also a 2017 BCAN John Quale Travel Fellow, for her research proposal, “Recombinant CCL2 as a Novel Treatment Strategy for Bladder Cancer.” Dr. Mukerjee is a post-doctoral fellow at University of Texas Health Science Center in San Antonio and her research is focused on studying how immune cells are recruited into the body environment.

Dr. Sarah Psutka, for her research proposal, “Quantifying Risk and Resilience Among Patients with Bladder Cancer: A Novel Personalized, Comprehensive Risk Stratification Program.” Dr. Psutka is an Assistant Professor at the University of Washington and her research proposal addresses the need to identify a more objective way for physicians to assess a patient’s ability to tolerate surgery.

The New Discoveries Research Young Investigator Award for Patient Centered Clinical Research was presented to Dr. Sumeet Bhanvadia for her research proposal, “Understanding the Burden and Impact of Financial Toxicity in Bladder Cancer—A Mixed Methods Study of Two Diverse Patient Populations.” Dr. Bhanvadia is Assistant Professor of Urology at the University of Southern California and her study is focused on assessing the extent of financial toxicity experienced by bladder cancer patients across a broad range of race, ethnicity, insurance type and socioeconomic status.

2019 John Quale Travel Fellows

Thanks to the generosity of donors, each year, BCAN awards John Quale Travel Fellowships, that enable early career investigators interested in bladder cancer to attend BCAN's annual Think Tank scientific meeting. To date, BCAN has supported 40 Quale Fellows, many of whom are now considered leaders in the bladder cancer community.



Lee Hugar, MD, University of Pittsburgh Medical Center

Mentors: Benjamin Davies, MD and Bruce Jacobs, MD, of University of Pittsburgh



Swathi Ramakrishnan, MD, Health Research Incorporated, Roswell Park Cancer Institute Division

Mentors: Gurkamal Chatta, MD and Anna Woloszynska, PhD, Roswell Park Comprehensive Cancer Center



Amy Lim, MD, PhD, University of Texas MD Anderson Cancer Center

Mentors: Colin Dinney, MD and Neema Navai MD, MD Anderson Cancer Center



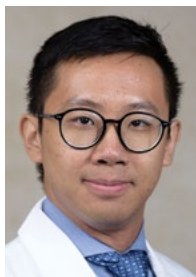
Samuel Washington, MD, University of California San Francisco

Mentors: Sima Porten, MD, MPH, Maxwell Meng, MD and Peter Carroll, MD, MPH, University of California San Francisco



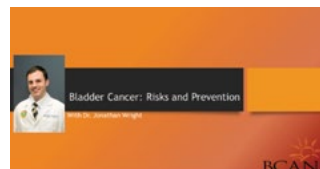
Amy Luckenbaugh, MD, Vanderbilt University Medical Center

Mentors: Sam Chang, MD, MBA, David Penson, MD, MPH, NMHC, Vanderbilt University Medical Center



Nathan Wong, MD, FRCSC, Memorial Sloan Kettering Cancer Center

Mentors: Jonathan Coleman, MD and Gopal Iyer, MD, Memorial Sloan Kettering Cancer Center



Patient Insight Webinars

In 2019, BCAN conducted 11 live, online programs, featuring leading clinicians in urology, radiation oncology, medical oncology and other areas, and viewers had direct access to these experts in real time to ask questions related to topics about their disease. Patient Insight Webinars enable participants to see and hear online presentations on important topics including bladder cancer diagnosis, treatment and quality of life.

Patient and Caregiver Support Services

While BCAN staff regularly respond to inquiries from patients, caregivers, family members, survivors and co-survivors, in 2019, BCAN's Survivor 2 Survivor (S2S) program matched 106 bladder cancer patients with survivors who have had similar experiences. These trained volunteers share their insights about bladder cancer diagnosis, treatment and survivorship issues with those who are following similar journeys.

Here's what webinar viewers had to say:

"I appreciated the presenter's wealth of knowledge and preparation for the broadcast, as well as their obvious commitment to engaging in this discipline geared toward decreasing suffering and increasing best outcomes."

"I liked that there were very honest responses as to what data is available and the effort to find out actual patient experiences such as with BCG and side effects."

"Great job, so informative! The format was great!"



Above: Diane Quale, BCAN Co-Founder presents the 2019 Best of BCAN award to Dr. Angela B. Smith.



Bladder Cancer Patient Summit

The fourth annual Bladder Cancer Summit for Patients and Families was held October 4-5, 2019. More than 150 attendees learned about bladder cancer advocacy, research engagement, and heard about some of the latest medical advances in bladder cancer treatment from nationally recognized experts in the field. It also included a session focused on caregivers with a doctor and caregiving expert who highlighted the unique roles and needs of the bladder cancer caregiver community.

Summit speakers discussed patient engagement in various facets of bladder cancer research such as comparative effectiveness

research, being a patient advocate in pharmaceutical industry trials, and participating in patient advocacy in the National Institutes of Health grant review process. In addition, a speaker from the Department of Defense highlighted the role of “Research Engagement: the DoD Patient Advocate Experience.”

Bladder Cancer Summit “Best of BCAN Awards” were presented to Karen Sachse, Dr. Neil Kurtz and Dr. Angela B. Smith, volunteers who exemplify aspects of BCAN mission with a dedication to bladder cancer education, awareness or research.



Lunch and Learn Live

BCAN's "Lunch and Learn Live" sessions educate patients and families about bladder cancer in their local communities, featuring presentations by local bladder cancer experts. BCAN partnered with our chapters and support groups as well as academic institutions and large urology practices nationwide to offer this program. Seven presentations for patients and their families were held in 2019.

These local "Lunch and Learn Live" programs increase patient understanding of the risks, diagnosis, staging and treatment of bladder cancer; involve local experts and their resources in the education of patients; to empower patients as active participants in their bladder cancer treatment; and to increase awareness of and access to BCAN programs and services.



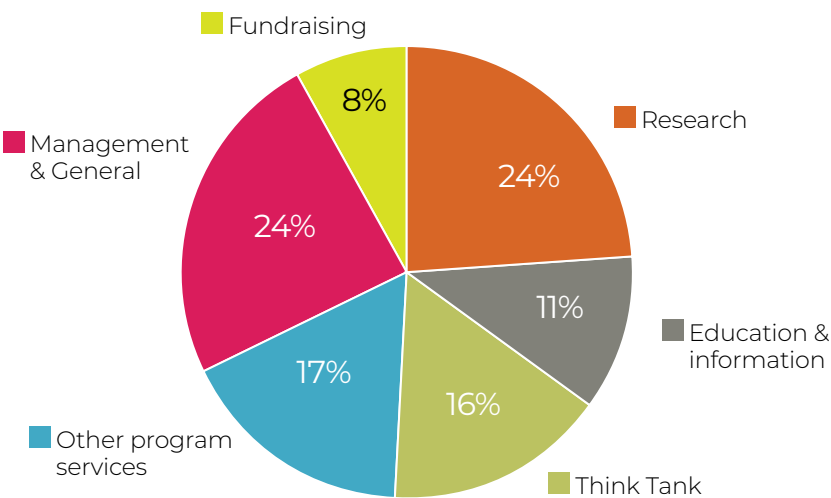
Comments from Lunch & Learn attendees:

"I really appreciate the opportunity to attend a symposium in person. The info is spot on and the ability to actually talk with experts is invaluable."

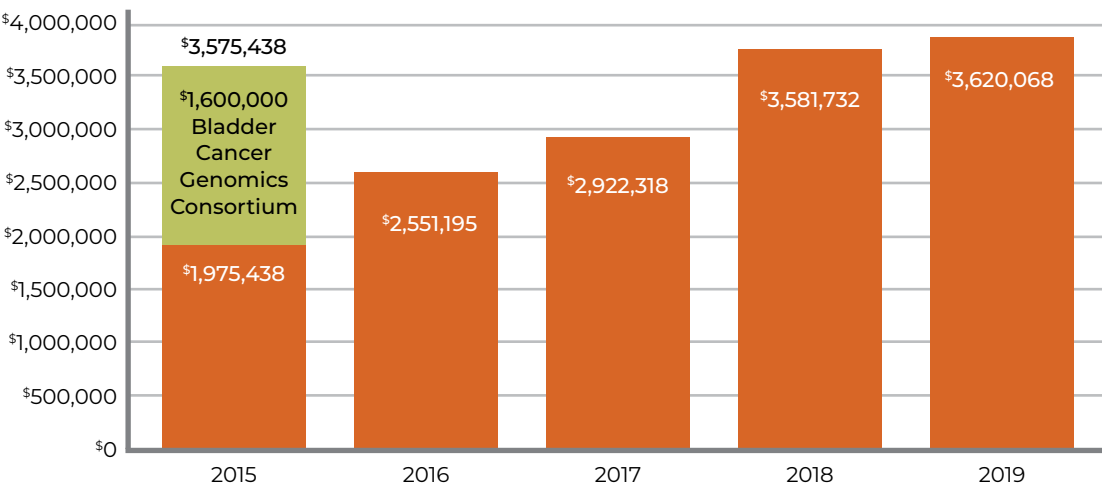
"Thank you for offering this valuable information session w/ the doctors and support staff."

2019 REVENUE AND EXPENSES

Expense Composition
.77¢ of Every Dollar goes to Mission Services



Bladder Cancer Advocacy Network
5-Year Revenue Chart 2015–2019



AWARDS & RECOGNITION



In 2019, for the **fifth consecutive year**, BCAN was recognized with the highest possible ranking, four stars, from Charity Navigator, America's largest independent charity evaluator, for our demonstrated track record of success and governance excellence. Charity Navigator's CEO, Michael Thatcher, said: "BCAN's exceptional 4-star rating sets it apart from its peers and demonstrates its trustworthiness to the public."



For the second consecutive year, the nation's most-influential nonprofit evaluator, Charity Navigator, named BCAN as one of "**America's 10 Best Medical Research**" organizations for being "committed to funding cutting-edge research and finding breakthroughs for a spectrum of conditions and diseases." BCAN is "also dedicated to using donors' funds wisely in their journey to find a cure."



A **GuideStar Seal of Transparency** indicates that a nonprofit has provided key information in its Nonprofit Profile. By providing up-to-date information, nonprofits allow potential donors and funders to make educated decisions about the work they do to make the world a better place.

2019 MAJOR DONORS

The following donors contributed \$500 or more to the Bladder Cancer Advocacy Network in 2019. Thank you for supporting our mission, as together we are leading the way to awareness and a cure for bladder cancer.

\$250,000+

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Genentech, Inc.
JPB Foundation

\$100,000 - \$249,999

Astellas/Seattle Genetics
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Gerald McNamara
and Renée Petrofes
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\$25,000-\$49,999

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\$5,000-\$9,999

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The following individuals, instrumental in our fight against bladder cancer, were celebrated with gifts in 2019.

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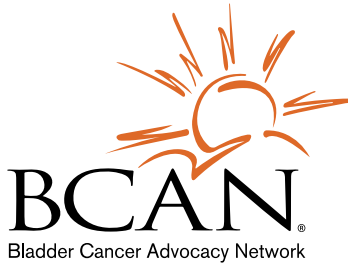
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