

Annual Report 2015

A Letter from Our Chair of the Board and CEO...

... A Year of Breakthroughs

Dear Friends,

It became apparent this year that all of us together are greater than bladder cancer. In fact, 2015 is best summarized as a breakthrough year. We doubled the number of patients reached through our programs and educational support services by empowering them with vital tools and information and embarked on the most promising research initiative in the Bladder Cancer Advocacy Network's (BCAN) ten-year history.

Advocacy efforts are critical to our mission and BCAN volunteer advocates are uniquely positioned and trained to respond to a broad array of issues involving bladder cancer. This year we heightened our efforts to shape and influence federal legislation by visiting members of Congress during our Hill day. In 2015, we were successful in securing a Senate resolution declaring May as "National Bladder Cancer Awareness Month" and thanks to the tremendous efforts of our volunteer advocates, voices of the bladder cancer community were heard all over the country.

BCAN observed its ten-year anniversary with celebration and reflection. This milestone commemorated with a gala recognizing the many volunteers and donors that helped to shape the organization into what it is today and by looking forward to the promises of tomorrow.

With the ultimate goal to provide every patient with the opportunity to be an exceptional responder to personalized therapy, BCAN launched the Bladder Cancer Genomics Consortium (BCGC). A collaboration of eight leading academic medical institutions, BCGC's first project is a large-scale genomics bladder cancer study.

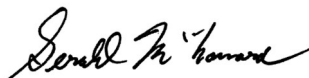
Our 2015 successes are a testament to the visionary leadership of Co-Founder Diane Zipursky Quale, and we are honored to continue building on her legacy.

Finally, as we move into the world with more emphasis on bladder cancer and our mission to increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community, we know that our progress is a result of the generosity of BCAN's supporters and volunteers. We remain grateful for your passion and commitment to a world free from bladder cancer.

With great appreciation for your support,



Andrea Maddox-Smith
Chief Executive Officer



Gerald McNamara
Chair of the Board



The Bladder Cancer Think Tank collaborated in North Carolina.



May was declared "National Bladder Cancer Awareness Month."



"BCAN TEN!" celebrated BCAN's ten-year anniversary.



BCGC was launched, focusing on personalized medicine.

National Bladder Cancer Awareness Month

114TH CONGRESS
1ST SESSION

S. RES. 187

Expressing support for the designation of the month of May 2015, as
“National Bladder Cancer Awareness Month”.

IN THE SENATE OF THE UNITED STATES

MAY 21, 2015

Mr. MENEZES (for himself, Mr. ISAKSON, and Mr. SCHUMER) submitted the
following resolution; which was considered and agreed to

RESOLUTION

Expressing support for the designation of the month of May
2015, as “National Bladder Cancer Awareness Month”.

Whereas 500,000 families in the United States live with bladder cancer;

Whereas more than 74,000 people are expected to be diagnosed with bladder cancer and 16,000 will die due to the disease in 2015 alone;

Whereas bladder cancer affects people of all ages and backgrounds and is among the top 10 cancers with the highest incidence rates in the United States;

Whereas bladder cancer is known as one of the most expensive cancers to treat on a per patient basis with a recurrence rate of approximately 50 to 80 percent, requiring lifelong surveillance;

Whereas bladder cancer symptoms, such as blood in the urine, are easily recognized, however, many are unaware of the threat of bladder cancer, often prolonging the time to diagnosis;

Whereas if diagnosed early, bladder cancer is treatable;

Whereas military veterans are twice as likely as nonveterans to be diagnosed with bladder cancer;

Whereas women are often diagnosed at a later stage in the development of bladder cancer, and when diagnosed at the same stage as men, women have a worse prognosis;

Whereas if diagnosis and treatment are delayed, the life expectancy of an individual with bladder cancer decreases;

Whereas the quality of life of a person with bladder cancer will depend on future treatment and diagnosis developments, which will rely on research advancements;

Whereas there have been no new treatments approved by the Food and Drug Administration for bladder cancer in over 10 years;

Whereas research advancements for bladder cancer are limited by lack of awareness about the disease within the medical community and general public;

Whereas increased awareness will promote early diagnosis and increase the chances of survival;

Whereas increased awareness will bolster public support of the disease and thus increase funding for innovative research and the development of new treatment options and diagnostic tools;

Whereas traditionally on the first Saturday in May each year, survivors, caregivers, and loved ones walk together throughout the United States to raise awareness of bladder cancer;

Whereas the Bladder Cancer Advocacy Network and its community of patients, caregivers, and specialists seek—

(1) to foster a community of hope and support;

(2) to fund and conduct research for innovative treatments and diagnostic tools; and

(3) to increase public awareness and understanding of bladder cancer; and

Whereas May would be an appropriate month to designate as “National Bladder Cancer Awareness Month”: Now, therefore, be it

Resolved, That the Senate—

(1) supports the designation of May 2015, as

“National Bladder Cancer Awareness Month”;

(2) supports the goals and ideals of National

Bladder Cancer Awareness Month; and

(3) calls on the people of the United States, interested groups, and affected persons—

(A) to promote awareness of bladder cancer and to foster understanding of the impact of the disease on patients and their families and caregivers;

(B) to take an active role in the fight to end bladder cancer; and

(C) to observe National Bladder Cancer Awareness Month with appropriate ceremonies and activities.



"BCAN TEN!" marked the celebration and reflection of our first decade, while inspiring future BCAN initiatives.





Walk for Bladder Cancer®

Leading the way to a cure

During the month of May, the bladder cancer community came together across the nation to raise awareness and funds.





**BLADDER
CANCER
GENOMICS
CONSORTIUM**

Creating the opportunity for every bladder cancer patient to be an exceptional responder

Introducing an innovative collaboration between the Bladder Cancer Advocacy Network (BCAN) and major medical centers to develop an enriched understanding of the genomic profile of bladder cancer and facilitate the development of novel therapeutics. This \$1.6 million investment through private philanthropy will increase collaborative research to improve outcomes for bladder cancer patients.

PRECISION MEDICINE IN BLADDER CANCER



The Cancer Genome Atlas (TCGA) results suggest potential therapeutic targets in 70% of bladder cancer tumors.



More than 32 genes have been identified as playing a critical role in bladder cancer biology.



Additional sequencing and sharing of data is needed to identify those molecular alterations that are most likely to be actionable and impacted by targeted treatments.

Pilot Project: UC-GENOME

Urothelial **C**ancer-**GENO**mic analysis to **i**mprove patient outcomes and **r**Esearch



Enroll 200 metastatic bladder cancer patients



Tumor tissue sent for Next Generation Sequencing (NGS) at no cost to patient or institution



Patients and their physicians receive a comprehensive report on potential treatments and clinical trials of novel therapeutics based on the genomic profile of their tumor



De-identified biospecimens and clinical information housed in a central biorepository and database for collaborative research opportunities

Study management provided by:



Next Gen Sequencing provided by:

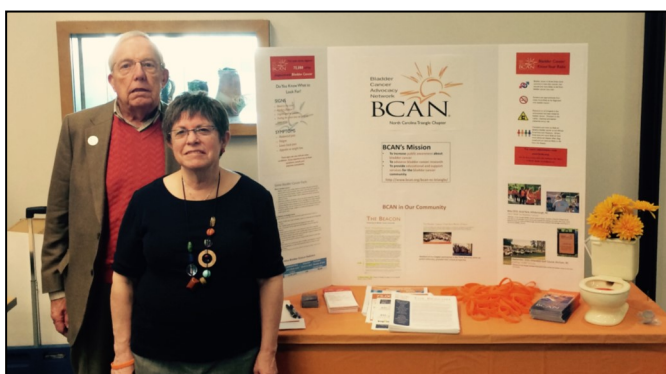




At the annual Bladder Cancer Think Tank, participants focused on identifying obstacles and creating solutions in bladder cancer research, fostering discussions to help define priorities for advancing bladder cancer research.



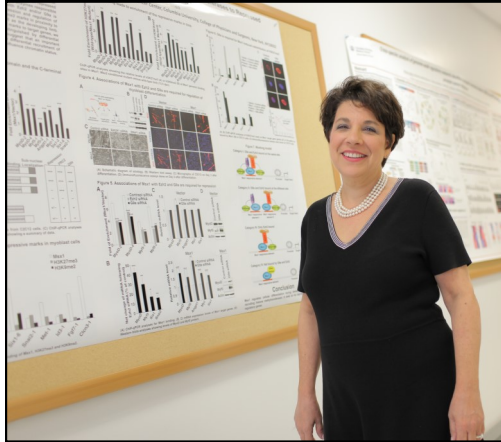
BCAN Memorable Moments



BCAN Volunteers, Chapters, and Support Groups made every effort to ensure the bladder cancer community was represented and had a strong voice from coast to coast through advocacy, fundraisers, health and lunch fairs.



2015 Bladder Cancer Research Innovation Award Winner



JAMES FAMILY FOUNDATION AND PARTNER FUND MANAGEMENT BLADDER CANCER RESEARCH INNOVATION AWARD

Cory Abate-Shen, Ph.D.

Professor of Urological Oncology at Columbia University Medical Center and Associate Director of Translational Research at the Herbert Irving Comprehensive Cancer Center
“Epigenetic regulation of bladder cancer progression.”

2015 Young Investigators

THE STEPHEN HALE GUSHÉE YOUNG INVESTIGATOR AWARD

Rahul Parikh, M.D., Ph.D.

University of Pittsburgh

“The Role of ATM Loss and the ATR-CHK1 Pathway in Bladder Cancer”



THE MIRIAM GLEBERMAN YOUNG INVESTIGATOR AWARD

Philip Palmbo, M.D., Ph.D.

University of Michigan

“The Role of TP63 and ATDC in Invasive Bladder Cancers”

2015 John Quale Travel Fellows

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Johns Hopkins Medical Institutions

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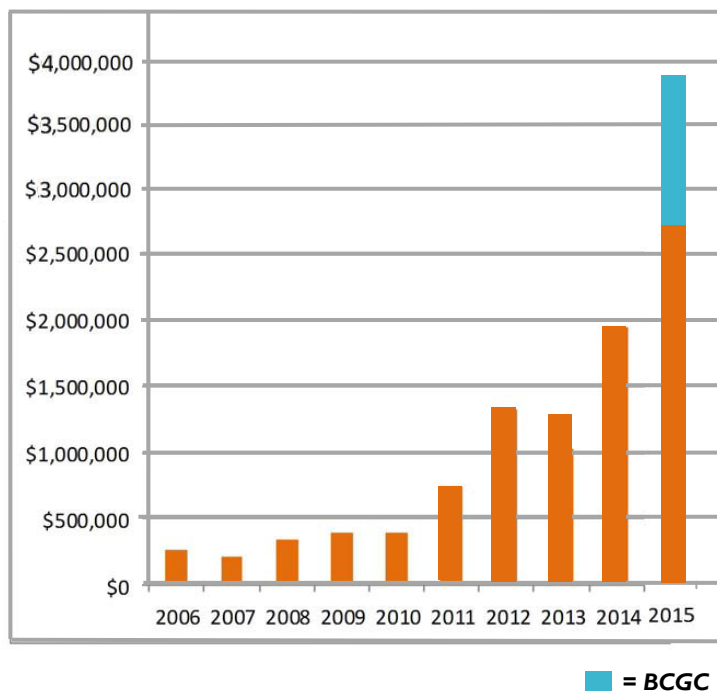
University of Chicago



2015: The Year at a Glance

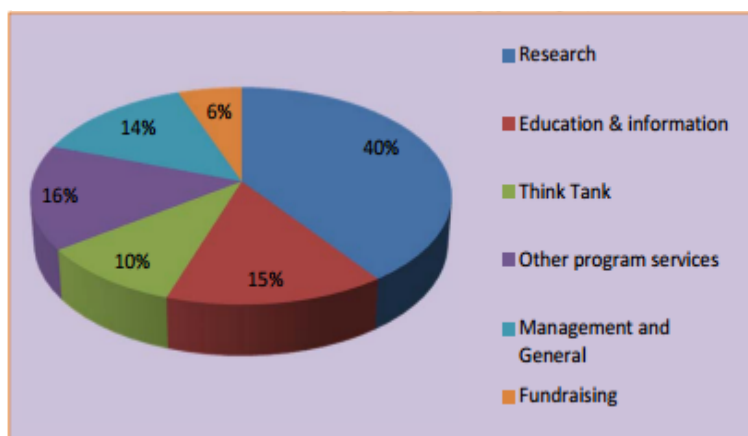
Income Growth

2015 Total = \$3,575,438



Expense Composition

2015 Total = \$2,061,030



Additional Highlights in 2015

BCAN launched the Survivor 2 Survivor program, connecting newly diagnosed patients with a volunteer survivor who provides their firsthand account of life with a bladder cancer diagnosis.

“The New Normal: Living with a Urinary Diversion” videos introduced eight bladder cancer survivors giving voice to their choice to let others know about living well with a urinary diversion.

The PCORI supported Patient Survey Network started with over 800 participants providing input on research questions that are important to bladder cancer patients.



Thank You to our Generous Donors

*The following list includes individual donors who contributed \$500 and higher between January 1, 2015 and December 31, 2015.
We appreciate the generosity of all of our supporters.*

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