

Bladder Cancer Advocacy Network **Newsletter**

THE BEACON | FALL 2021 | BCAN.ORG

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BCAN Funds the Next Generation of Leading Bladder Cancer Researchers

n May 2021, BCAN announced our record five New Discoveries Research Young Investigator Awards supporting the development of outstanding early career research scientists and clinical cancer research investigators who have shown a commitment to improving the lives of bladder cancer patients. This was the first year that BCAN has presented five awards — evidence of both the volume and quality of worthwhile applications received, and the generous support of donors.

Supporting Early-Career Investigators

Each Young Investigator Award provides a \$50,000 grant that supports one year of early-career bladder cancer research. Since 2009, BCAN has awarded more than \$6 million to promising scientists and research investigators across the country and these awards demonstrate the important work to improve the understanding of bladder cancer and its impact on patients and families continues.

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Dr. Svetlana Avulova



Dr. Filipe Carvalho



Dr. Brendan Guercio



Dr. Benjamin Miron



Dr. Eugene Pietzak

THE BLADDER CANCER ADVOCACY NETWORK 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...



Bladder cancer research is today's engine that drives tomorrow's improved outcomes for patients. The Fall edition of the BCAN newsletter is among my favorites because its theme is bladder cancer research and the role that all of us play in it. Since 2016, there have been numerous scientific breakthroughs giving patients treatment options that did not exist before. These breakthroughs came about only because of increased focus on bladder cancer research.

In the pages that follow, you'll read more about the dedicated research professionals who have devoted their careers to defeating bladder cancer, the heroic patients who have opted to be part of clinical trials as well as the countless volunteers and advocates who have helped BCAN further our mission.

Bladder cancer research was on display at our recent bladder cancer Think Tank, the premier scientific meeting in North America that provides a collaborative setting contributing to solutions in bladder cancer research and treatment. I came away heartened by the number of exceptional scientific and healthcare professionals who have devoted their careers to developing new ways to diagnose and treat bladder cancer.

Generosity fuels scientific progress and this year, we will award more than one million dollars to fund research that offers scientists the opportunity to seek and test new ways to improve outcomes for bladder cancer patients and those who love them. It is only through the kindness of donors like you that research and patient education and support are possible.

If you would like to make a donation to help us continue our progress against bladder cancer, please visit bcan.org/donate or return your gift in the envelope provided with this newsletter.

Andrea Maddox-Smith Chief Executive Officer

P.S. As always, I love hearing from you. If you have questions, comments or other thoughts, please feel free to contact me via email at amsmith@bcan.org or by phone at 301-215-9099, extension 201.

2021 Awardees

Two 2021 BCAN New Discoveries Young Investigator Awards went to clinical scientists at Memorial Sloan Kettering Cancer Center in New York City. The first was awarded to Brendan Guercio, MD, a Hematology/ Oncology Fellow for his project titled "Associations of Patient Diet and Benefit from Immunotherapy in Urothelial Carcinoma." The second award was presented to Eugene Pietzak, MD, Assistant Attending Surgeon (Urologic Oncology) in support of his project titled "Defining the Clinical Impact and Molecular Drivers of 'Secondary' Muscle-Invasive Bladder Cancer."

The two 2021 Palm Beach New Discoveries Young Investigator awardees are Filipe De Carvalho, MD, Ph.D., a Urologic Oncology Fellow at Brigham and Women's Hospital in Boston, and Benjamin Miron, MD, Medical Oncology Fellow at Fox Chase Cancer Center in Philadelphia. The title of Dr. Carvalho's awarded project is "Clonal Architecture and Tumor

Microenvironment of Cisplatin Resistant Localized Muscle Invasive Bladder Cancer" and Dr. Miron's is "Relationship of Circulating Tumor DNA in Patients with Muscle Invasive Bladder Cancer to Pathologic Staging and Disease Prognosis."

The 2021 BCAN New Discoveries Young Investigator Award for Patient Centered Research was awarded to Svetlana Avulova, MD, Urologic Oncology Fellow at Mayo Clinic. Dr. Avulova's project is titled "Sexual Function in Women Undergoing Radical Cystectomy."

Jared Sher, Chairman of the Board of Directors at BCAN, commented that "It is our distinct pleasure to invest in such promising early-career investigators and to support their quest to develop innovative approaches to improve the lives of bladder cancer patients and those who love them. We also appreciate the generosity of our donors who help make these awards possible, fueling today's research to provide tomorrow's improved outcomes." 1

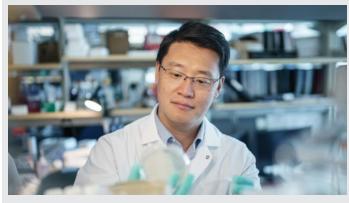
Fueling New Approaches to Bladder Cancer Research

The Bladder Cancer Advocacy Network (BCAN) was founded in 2005 in part because Diane and John Quale were shocked by the scant attention paid to bladder cancer and the lack of research funding to find better ways to treat this disease. When John was diagnosed in May 2000, they quickly learned that treatments had not changed in 30 years.

BCAN's Bladder Cancer Research Innovation Awards (RIAs) support exceptionally innovative and creative projects that offer non-traditional or out-of-the-box thinking that can lead to new ways to transform bladder cancer patients' lives. In July 2021, BCAN announced the recipients of its RIA, the first year in which two awards have been granted, reflecting both the quality and volume of applications as well as the generosity of the BCAN community.

2021 Award Recipients

This year's awardees were Weiguo Cui, Ph.D., an Associate Investigator at the Versiti Blood Research Institute and an Associate Professor of Microbiology and Immunology at the Medical College of



Weiguo Cui, Ph.D.

Wisconsin, and John K. Lee, M.D., Ph.D., an Assistant Professor in the Human Biology Division at the Fred Hutchinson Cancer Research Center. These awards are the latest additions to BCAN's grant portfolio.

Their bladder cancer research projects

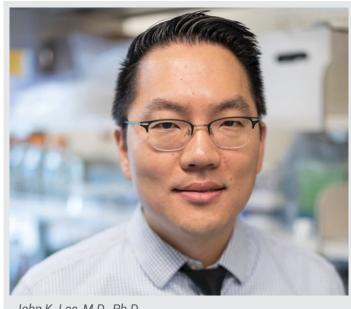
Dr. Cui's project involves discovering what factors lead to T cell exhaustion and finding ways to reverse it. T cells are a part of the immune system that focus

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on specific foreign particles. One of his proposed technologies is designed to convert exhausted T cells into energized T cells to attack and treat bladder cancer, preventing cancer recurrence and metastasis. Dr. Cui told BCAN, "We are very grateful for the generous support which will propel our research forward to find new treatment opportunities for bladder cancer patients."

Dr. Lee's project is designed to develop a better understanding of variant bladder cancers. Its goal is to inform new and effective treatment strategies for those suffering from these cancers. Dr. Lee said, "The BCAN Research Innovation Award will provide timely and important support to our work to better understand rare types of bladder cancers. Little is known about this group of diseases which are often more lethal than conventional bladder cancers. Our hope is that these studies will provide new insights into how variant cancers arise and are maintained with the goal of informing more effective treatments for patients."

Drs. Cui and Lee are recognized experts in their fields. Among other disciplines, Dr. Cui's expertise is in effector and memory T cell differentiation, and Dr. Lee's is in molecular targets that could form the basis of immunotherapy-based therapeutic strategies.



John K. Lee, M.D., Ph.D.

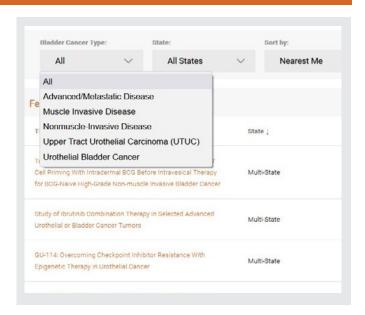
Jared Sher, BCAN's Chairman of the Board, noted "BCAN is pleased to fund Dr. Cui's and Dr. Lee's novel projects. These research grants will help advance the type of high risk, high reward bladder cancer research that can help patients and those who love them. We also are deeply grateful for the generosity of our donors, who have enabled us to offer two \$300,000 Research Innovation Awards for the first time ever." 🊹

Bladder Cancer Clinical Trials

clinical trial is a research study that tries to find better ways to prevent, screen for, diagnose, or treat a disease like bladder cancer. When you are facing bladder cancer, a clinical trial might be your first option rather than your last resort. BCAN helps connect patients and caregivers with information about clinical trials through our bladder cancer Clinical Trials Dashboard.

In the Dashboard, you can search for clinical trials that might be right for you. In addition, visitors can search by the type of bladder cancer you or your loved one has, by your state of residence, and you can even sort the results by those clinical trials that are closest to you. You can also print out a copy of information about a clinical trial and take it with you to your next doctor's appointment.

We encourage you to visit bcan.org/clinicaltrials today.



Long time BCAN Patient Advocate Describes the Value of Research

ladder cancer patient and BCAN's longstanding volunteer, Robert Lipman, first heard about John and Diane Quale and the Bladder Cancer Advocacy Network (BCAN) in 2005. Bob was diagnosed with high grade non-muscle invasive bladder cancer that vear and like BCAN's co-founders. John and Diane Quale, was surprised at the lack of information available about the disease. In fact, because there were no available educational resources for patients at the time, Bob's local urologist drew diagrams on the back of a folder to explain the different layers of the bladder, and what bladder cancer was. Bob went to see Dr. Mark Schoenberg, then at Johns Hopkins, to seek a second opinion on his bladder cancer since it did not respond to the first round of BCG treatments. Bob asked, "Why isn't there an advocacy group for bladder cancer?"

Dr. Schoenberg told Bob, "Well, one of my patients and his wife are forming an advocacy group," and that happened to be John and Diane Quale. As it turned out. Bob and the Quales lived in the same town. Bob called John and Diane and soon after, he went to visit with them. All shared their frustration that bladder cancer simply did not get the attention it deserved

Soon after talking with the Quales, Bob began volunteering at BCAN doing whatever needed to be done to support the organization. While BCAN began at John and Diane's kitchen table, Bob remembers walking from his house to BCAN's first-ever office space, a townhouse in Bethesda, Maryland, to stuff envelopes.

The importance of bladder cancer research

The meaning and value of bladder cancer research became apparent to Bob when he read his first scientific paper about a medical study using BCG and Interferon, a drug that stimulates the body's immune system to find and kill cancer cells. Bob took the paper to his local urologist and after reading the



Bob Lipman and Diane Zipursky Quale at the kickoff of then Vice President Biden's Cancer Moonshot in 2016.

paper carefully, the doctor agreed to treat Bob using the combination of the two drugs. One of the paper's authors was Dr. Michael O'Donnell, who serves on BCAN's Scientific Advisory Board. Bob noted that, after some initially disappointing results, treatments with BCG and Interferon ultimately prevented the tumor in his bladder from recurring and he has remained cancer-free for the last 16 years.

Having been one of the original BCAN patient advocates, Bob has a unique view of the value of bladder cancer medical research. He told BCAN, "It gives me and all the other patients and caregivers a lot more hope. Thanks to research, now there are many more treatments and therapies for bladder cancer patients in all stages of the disease." He added, "When I had bladder cancer, my options were limited to BCG or having my bladder removed."

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Funding Research to Help Bladder Cancer Patients

BCAN invests in the people who have dedicated their careers to improving outcomes for bladder cancer patients. The ways that BCAN helps researchers include:

JOHN QUALE TRAVEL FELLOWSHIP

Since 2009, making it possible for early-career investigators interested in bladder cancer research to attend the annual Bladder Cancer Think Tank Meeting.

YOUNG INVESTIGATOR **AWARDS**

Supporting the development of outstanding early career research scientists and clinical cancer research investigators who have shown a commitment to improving the lives of bladder cancer patients.

BLADDER CANCER RESEARCH INNOVATION AWARD

Funding exceptionally novel and creative projects with tremendous potential to produce breakthroughs in bladder cancer research to improve patient outcomes.

CAREER DEVELOPMENT AWARD (NEW IN 2022)

Supporting researchers who have established an independent bladder cancer research program and a successful career path.

Some of the Bladder Cancer Researchers and Medical Professionals BCAN Has Supported Through the Years















That's a Wrap! Think Tank 2021

n August 6 and 7, 2021, BCAN hosted its 16th annual Bladder Cancer Think Tank. This is the second consecutive year that North America's premier bladder cancer scientific meeting was held online. More than 375 bladder cancer researchers, doctors, and patient advocates gathered online to collaborate and advance bladder cancer research and advocacy.

Meeting attendees included leading urologists, oncologists, researchers, pathologists, social scientists, patient advocates and industry representatives, all of whom are dedicated to improving the diagnosis, treatment and survivorship of bladder cancer. BCAN's Think Tank facilitated important discussions to define some of the current priorities for advancing bladder cancer research, including all parts of the patient and caregiver journey, from diagnosis to treatment to survivorship.

This year's program included sessions focused on a diverse set of themes, including:

- BCG Shortage Update: Alternatives in the Market
- Artificial Intelligence Emerging and Evolving Roles in Bladder Cancer
- · Biologic Sex Differences in Bladder Cancer
- Integrating Complementary and Alternative Medicine in Bladder Cancer Care
- Long Term Management of Urinary Diversions
- BCG Unresponsive Non-Muscle Invasive Bladder Cancer

Additional Think Tank highlights included a presentation from Michael M. Shen, Ph.D., about the research that he has conducted as part of his 2018 Research Innovation Award, as well as introducing six 2020 John Quale Travel Fellows (JQTFs). Prior to the pandemic, when Think Tank meetings were held in person, the John Quale Travel Fellowship Program made it possible for early-career investigators interested in bladder cancer research to attend the Think Tank Meeting.

The 2021 Think Tank was not all about presentations and science, though. This year was the first-ever "BCAN's Got Talent" show featuring members of the community who demonstrated their own once-hidden talents, including



Panelists discuss the BCG shortage during the online Think Tank 2021.



Bill Russell, BCAN patient advocate, plays the drums to his "Think Tank Blues" song.

drumming, piano playing, a "Stupid Human Trick," and some amazing vocals. Reaction to our talented community members was so positive that many requested that we have an in-person talent show in vears to come.

Building on the success of the 2021 Think Tank, we all remain hopeful that we can meet in person next August in Denver, CO for the 17th annual meeting.

Strengthening the BCAN Research Team

n August 2021, BCAN welcomed Rebecca Barasky, MPH, as BCAN's new Director of Research. For some time, Dr. Stephanie Chisolm managed both education and research but due to BCAN's unprecedented growth, it was important to have full time staff leadership in both areas.

Rebecca is responsible for the day-to-day operational oversight and management of all grant activities including application solicitation, grants management, investigator support, and analysis of program efficiency. Rebecca also manages BCAN grants from pre-award through award closeout while working closely with BCAN's senior management team and Board to successfully achieve desired research outcomes.

Rebecca's Background

Rebecca has been advancing research efforts that prioritize patients for over a decade. Prior to joining BCAN, Rebecca was the Associate Director, Science Operations, Clinical Effectiveness and Decision Science at the Patient Centered Outcomes Research Institute, (PCORI). While at PCORI, Rebecca managed the pre-award and funded award processes ensuring rigorous, active portfolio management and adherence to PCORI's policies and procedures. She also supervised cross-departmental organizational priorities like the development of rapid funding mechanisms and novel PCORI funding announcements to respond to the COVID-19 pandemic.

Prior to PCORI, Rebecca was the scientific manager for the NIH-funded DC Center for AIDS Research at the George Washington University, where she managed the pilot awards program, identified strategic areas for RFAs, coordinated the pre-award consultation process and managed the application and scientific review process.

In her free time, Rebecca enjoys spending time with her family, cooking, all things fitness-related, and adventures with her 70-pound Shepherd mix, Winston.



BCAN's new Director of Research, Rebecca Barasky, MPH

Rebecca holds a Master of Public Health from George Washington University and a Bachelor of Arts from the University of Michigan.



For seven consecutive years, BCAN's strong financial health and commitment to accountability and transparency earned it a 4-star rating from Charity Navigator, America's largest independent charity evaluator.

Only 7% of all charities ranked have scored this high for seven consecutive years and we are proud to be good stewards of our donor's generous contributions.

Bob as a bladder cancer patient advocate

Bob's volunteering was not limited to stuffing envelopes. On two occasions, Bob testified for more and better bladder cancer treatments at the U.S. Food and Drug Administration. He told BCAN "I testified as the patient voice, advocating for better research and better treatments."

Bob's volunteering to help bladder cancer patients goes even further. He is also a volunteer in BCAN's Survivor to Survivor (S2S) program that connects newly diagnosed bladder cancer patients with trained volunteers who offer their perspectives on what it was like for them to be diagnosed and treated. S2S is about lending a sympathetic and knowledgeable ear to those who could benefit from someone who has "been there, done that." He enjoys helping others in their bladder cancer journeys.

The value of research collaboration

Bob also sees the value in BCAN's contributions to bladder cancer research outside of the financial grants that the organization gives to develop new and innovative ways to treat bladder cancer. Bob told BCAN. "A lot of bladder cancer research has come about because of the work that BCAN has done to bring together the researchers who collaborate and share information." An example of enhanced collaboration is BCAN's annual bladder cancer Think Tank, the premier bladder cancer scientific meeting in North America. Since its inception in 2006, the Think Tank meeting has focused on identifying obstacles and creating solutions in bladder cancer research. Think Tank attendees have told BCAN that the very nature of the meeting helps makes collaboration possible, and that many attendees form professional relationships that last for their entire careers. You can read more about the Think Tank on page 8.

Bob noted that the quantity of people researching improved bladder cancer treatments has changed over the years as well. "In the beginning, bladder cancer research was being conducted primarily by doctors and researchers at academic institutions." Bob noted. "Now with enhanced collaboration, pharmaceutical companies and others have invested in bringing new treatments to the market." For those



Bob and BCAN co-founder Diane Zipursky Quale at the BCAN table a 2006 health expo



Bob Lipman and his daughter at the first Walk to End Bladder Cancer in 2010



Bob receiving a "Best of BCAN" award at the first Summit for Bladder Cancer Patients and Families in 2016

723,000 people who are living with bladder cancer in the United States, this increased focus means more treatment options and improved patient outcomes.

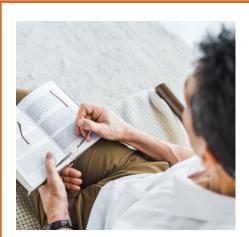
Patient involvement in clinical trials

Having been a bladder cancer patient turned volunteer and advocate, Bob feels strongly about another important research-related topic: getting patients involved in bladder cancer research. Patients offer crucial perspectives that create better clinical trial designs that improve the lives of those suffering from the disease. Bob believes that successful treatments and promising clinical trials mean involving patients from the outset to hear their perspectives. He said, "I have been involved in clinical trial designs to help ensure the patient perspectives are heard. It's been very gratifying to be able to make an impact on the medical community with the patients' perspective. Never in my wildest

dreams would Lever think that I would be a coauthor on papers in medical journals."

Watching BCAN grow over the years

As someone who's been involved with BCAN from the beginning and who has witnessed the organization's growth over the years, Bob stated that his sense of pride in BCAN stems from being involved in patient-centered research as well as being active in the Bladder Cancer Summit for Patients & Families. The Summit is an annual meeting in which bladder cancer patients, caregivers and advocates gather in person or online to share perspective, stories, and sometimes tears. Bob reflected that the Patient Summits are important to him. "It's so powerful for me to participate in a gathering like the Summit and to be able to interact with others like me."



The Gift that Keeps on Giving - Monthly

A recurring donation (the same amount donated each month) to BCAN will help us continue our critical work of helping bladder cancer patients and those who love them. For example, a \$50 monthly donation will enable us to deliver multiple copies of our most popular publications to newly diagnosed patients and their families.

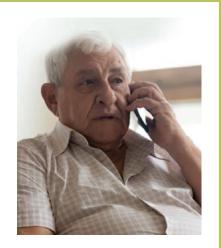
You can set-up your monthly donation today at bcan.org/donate.

Survivor to Survivor

Sometimes, you just need to talk to someone who truly understands.

BCAN's Survivor to Survivor program offers phone support for bladder cancer patients who have questions about their bladder cancer journeys. Many patients want to know more about things like what to expect with a surgery or procedure, what to expect with treatment, and how other survivors approached getting back to "normal."

If you are a bladder cancer patient and would like to be matched with a survivor, please call 301-215-9099 and leave a message at extension 212. You can also send a confidential email to mstout@bcan.org.



A New Era in Bladder Cancer Research

avid DeGraff, Ph.D., is an assistant professor at Penn State and a bladder cancer researcher who has been involved with BCAN for more than ten years. He and his colleagues at Penn State study bladder cancer tumor heterogeneity, the differences between tumors of the same type in different patients, and between cancer cells within a tumor.

In 2011, Dr. DeGraff was introduced to the BCAN community as a John Quale Travel Fellow, receiving a grant that underwrote his travel and lodging to attend the Bladder Cancer Think Tank. It was his first opportunity to think about a career focused on bladder cancer research since most of his work up to that point had been in prostate cancer.

"I Want to be a Bladder Cancer Researcher."

It was after the 2011 Think Tank that David saw bladder cancer research, in his words, as "a great opportunity for discovery and improvement." He noted that bladder cancer treatments had not advanced for many years and at the time, most of the options available for patients were chemotherapy, BCG treatments and/or bladder removal.

Speaking fondly of the Think Tank, Dr. DeGraff commented that its "warm atmosphere" and fellow attendees are collaborative and encouraging. He also noted that even from his first Think Tank, many people he met are those with whom he continues to work to this very day. Ultimately, after his first Think Tank, David said "I want to be a bladder cancer. researcher."

Dr. DeGraff began to focus professionally on bladder cancer research and just two years later, he received BCAN's Young Investigator Award (YIA) for his proposal to study bladder cancer tumorigenesis, the initial formation of a tumor in the body. The YIA supports the development of outstanding early career research scientists and clinical cancer research investigators who have shown a commitment to improving the lives of bladder cancer patients. More on the YIA on Page 1.



David DeGraff, Ph.D.

David noted that BCAN's initial grant made it possible for him to generate preliminary data that allowed him to secure another grant from the American Cancer Society. The second award enabled him to continue the project that was initially funded by BCAN. Dr. Degraff noted "The Young Investigator Award helped tremendously and enabled us to ask some very important scientific questions about bladder cancer." David said that the YIA also made it possible for him to study how bladder cancer tumors change and adapt, making some treatments no longer effective. By studying how tumors shift, it enabled researchers and doctors to offer more personalized treatment approaches.

Medical Research is a Calling

David has also attended BCAN's annual Patient Summit, an in-person and sometimes online gathering in which bladder cancer patients and

caregivers meet to support each other, share information, and learn about the current state of bladder cancer research and treatments. Dr. DeGraff explained, "As a scientist, meeting people who have been impacted by bladder cancer is very powerful. I think that medical research is a calling and that meeting patients and caregivers reinforces why it's so important to keep working hard to better understand the disease."

As for BCAN's contribution to bladder cancer research. Dr. DeGraff noted "I think the number of researchers who are studying bladder cancer has increased because of the work BCAN has done. The organization has done a very good job of offering a collaborative forum to talk about great ideas for bladder cancer research and treatment."

Dr. DeGraff has given back to the bladder cancer community as chair of the Young Investigator Award application review committee. He noted humorously that "...the applications are tremendous and I'm glad I am not competing now." He also said that the quality of bladder cancer research has significantly improved – a direct result of the collaborative network that BCAN has built

Research Advances

DeGraff noted significant advances in bladder cancer treatments such as the development and application of immunotherapy, using the body's own immune system to identify and destroy cancer cells.

He also lauded bladder cancer patients as a critical part of the research team, including those who enroll in clinical trials to advance knowledge about the disease, to donors and benefactors who make research possible through their financial contributions.

Asked what he would like bladder cancer patients to know about the current state of medical research, Dr. DeGraff responded that "there are people thinking about bladder cancer all the time. There are exceptional individuals working to improve outcomes for patients 24 hours a day, seven days a week." He also added, "We're at the beginning of a new era of finding treatments for bladder cancer."

Exercise Your FreeWill

Did you know that only 30% of Americans have completed a Will? Each of us know it's something that should be done but many simply never get it done.

As a benefit for members of the BCAN community, we have partnered with FreeWill, a company that provides an easy online way for you to create your own Will - FOR FREE. FreeWill has been trusted by over 300,000 Americans to safeguard their futures.

To learn more, please visit bcan.org/FreeWill

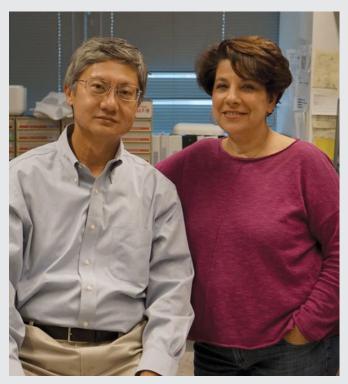


The Bladder Cancer Research Power Couple

usband and wife team, Michael Shen, Ph.D. and Cory Abate Shen, Ph.D. of Columbia University Irving Medical Center are researchers looking to improve outcomes for bladder cancer patients as well as former recipients of the BCAN Research Innovation Awards (Cory in 2015 and Michael in 2018). They represent a "power couple" in bladder cancer research and are leaders in the field of urologic oncology. Dr. Abate-Shen is the Chair of the Department of Molecular Pharmacology and Therapeutics at Columbia. Dr. Michael Shen is a Professor of Medical Sciences. Genetics and Development and the co-leader of the Tumor Biology and Microenvironment at the Herbert Irving Comprehensive Cancer Center, also at Columbia University. Both work hard to better understand bladder cancer. Their efforts are aimed at enabling the research and clinical community to find new and better treatments for patients.

Cory described her work developing geneticallyengineered mouse models that help study and understand what happens during the early stages of bladder cancer. Offering an example, she described how her lab collaborated with James M. McKiernan, M.D. at Columbia University (who is also on BCAN's Scientific Advisory Board) because Dr. McKiernan wanted to study if giving bladder cancer patients multiple doses of chemotherapy directly in their bladders could delay progression to high risk or muscle-invasive disease. Dr. Abate Shen's lab first tested that concept in mice. After conducting her study, Columbia researchers discovered that chemotherapy given directly in the bladder did slow disease progression. Based upon the results of the mouse model study done in Dr. Abate Shen's lab, Dr. McKiernan set up a clinical trial in humans which showed the effectiveness of locally administered chemotherapy. The encouraging trial results were published in 2021.

Michael's lab has been developing a biobank of patient-derived bladder tumor organoids, a collection of living tumor "avatars" for use in research to improve the understanding of health



Michael Shen, Ph.D.and Cory Abate Shen, Ph.D.

and disease. He noted that these organoids capture the histopathologic and molecular properties of their corresponding patient bladder tumors and can therefore be grown in the laboratory and used to study patient-specific features of the disease. He stated gratefully that part of the expansion of the biobank has been funded by BCAN. Dr. Shen further noted that by growing these tumor organoids, researchers can test patient-specific responses to treatments in the lab, with the hope of developing new and better treatments for use in bladder cancer patients.

Bladder cancer research

The state of bladder cancer research, while improving, is not where Dr. Michael Shen wants it to be. He noted that bladder cancer research has been underfunded for far too long and called out the lack of research dollars compared to other common cancers. He praised BCAN for funding research, adding that BCAN makes a "huge difference" by

providing grants for studies to test new ways to diagnose and treat the disease, often studies that are not likely to be funded by other grant sources.

Dr. Shen also added that during the last few years, there have been several new treatments approved for use in bladder cancer patients, but there is still much work to be done to understand drug resistance and how to predict the best response to treatments.

Patients are at the heart of bladder cancer research

Though not medical doctors themselves, patients remain the focus of Dr. Shen and Dr. Abate Shen. Cory noted that she would like patients to know that there are researchers who are completely dedicated to understanding the causes of bladder cancer and are working to inform new and better treatments. She also said that treatment without understanding the fundamental causes of bladder cancer is like giving therapies to a patient with blinders on, noting "major, clinical, fundamental changes are going to come from better understanding the disease."

Michael would also like patients to know that new and better treatments will come from scientists collaborating with clinicians. "You cannot do one without the other," he said, adding that solutions will come from cooperation and focus.

Dr. Shen added that patients play a critical role in advances in bladder cancer research. He noted that advocacy groups like BCAN give a platform for patients to demand more and better treatments. He stated that an active group of patient advocates calling for better funded research can be "transformative."

Dr. Abate Shen underscored how important it is for scientists and doctors to collaborate and noted again that patients also play a critical role because "everyone needs to be on the same page. We learn from them and they learn from us." She added that BCAN plays an important part in bringing these groups together.

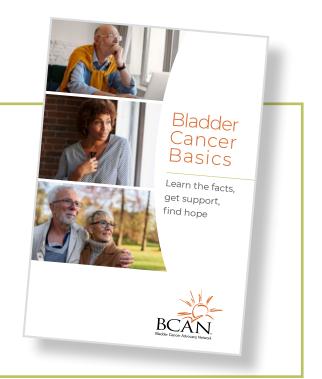
Michael urges BCAN and the bladder cancer community to continue to raise awareness of bladder cancer in the hopes that it will encourage more patients to talk about their experiences with the disease. He said that many patients are reticent to talk about their bladder cancer because in some ways, there is still a stigma attached to it. Dr. Shen believes that patients and caregivers advocating for more research funding have a powerful impact upon the elected officials who set budgets and allocate research funds. He added. "advocates can make a difference and that will compel politicians to understand the urgency."

Cory agrees, adding that she wants advocates to know how much power they have that can impact federally funded research. "Their (your) voices matter," she said.

Bladder Cancer Basics for the Newly Diagnosed

The newest edition of BCAN's handbook is now available. free of charge, to help bladder cancer patients and their caregivers learn about their diagnosis and treatment options. Bladder Cancer Basics contains more than 50 pages about bladder cancer signs, symptoms, diagnosis, treatment and survivorship. Download your free copy today.

www.BCAN.org/handbook





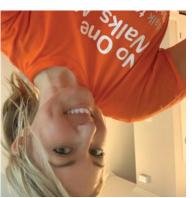
Leading the way to awareness and a cure

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To register visit **bcanwalk.org** or text WALK to **1-888-901-BCAN (2226)**.

The 2022 Walk to End Bladder Cancer will be held virtually across the county and inperson in select cities. If you or your loved one has been impacted by bladder cancer, the Walk to End Bladder Cancer is a great way to increase awareness about bladder cancer in your community.

Walk to End Bladder Cancer