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How a Second Opinion Saved Margo's Life

Margo was 57 at the time of her bladder cancer diagnosis in early 2020, just as COVID was beginning to impact the world. It was not until she received a second opinion that she knew how critical her situation was.

Before being diagnosed with bladder cancer, Margo lived a normal, healthy life. She wasn't a smoker, had no history of cancer, and had no known exposure to chemicals. After noticing blood in her urine, she knew that was odd, but not once did she think it was a sign of a much bigger problem. Margo decided to have her urine checked and thought to herself, "Okay, they're probably going to come back with a UTI." She did not have any discomfort or other symptoms, but she went to see her OB/GYN.



Margo and Dr. Ashish Kamat at the 2022 BCAN Think Tank.

Looking for answers

Some time went by, and Margo received the results of her urinalysis. To her surprise, they did not find any bacteria. She had done some research on the internet about blood in one's urine and what she read was troubling, so she quickly found a urologist. The urologist recommended that she get an MRI and cystoscopy.

The results from the MRI did not show anything and Margo interpreted that as good news. Because the MRI came back clear, she did not need to do a cystoscopy. Her doctor insisted she have one.

Margo told BCAN, "Having to think, 'Do I have cancer? Do I not have cancer?' is tough to ponder." The day before Margo's birthday, on December 27, she went in for the cystoscopy. Her results returned, and her doctor found a "lesion." With a sense of urgency in his voice, the doctor told Margo that he wanted to do a TURBT (trans urethral resection of bladder tumor) procedure, remove the lesion, and have it sent off for analysis.

Continues on page 3 >

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.

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A Note From Andrea...



If you know BCAN, you know that patients are at the heart of everything we do. In addition to providing free educational programs and support services for patients and their loved ones, we also fund bladder cancer research. Medical research is planting today's seed that will blossom with tomorrow's improved outcomes for bladder cancer patients and those who love them.

Our research investments over the years have varied from helping doctors investigate new ways to detect and fight bladder cancer to quality-of-life research for those living with it. Given the abundance of treatment options available now with more on the way, it's amazing to think that until 2016, the way in which bladder cancer was treated had not changed in three decades. While we have seen good progress, it is my belief that it's not enough. Our patients and their loved ones deserve more new and effective treatment options. In the pages that follow, you'll read more about how the bladder cancer community is working together to make this happen.

In this newsletter, you'll read a patient story about a woman whose life was saved by getting a second opinion, how more than 200 bladder cancer researchers and medical professionals came together to improve the lives of patients at our Think Tank meeting in August, as well as two new research awards that BCAN is offering to spark new approaches and treatments.

Funding this exciting research would not be possible without the generosity of people like you and we are so grateful for your support. If you would like to donate to help fuel more research, please visit bcan.org/donate.

P.S.: I love hearing from the members of the BCAN family. Please feel free to reach out to me via email at amsmith@bcan.org or by phone at 301-215-9099, extension 201.

Sincerely,

Andrea Maddox-Smith
Chief Executive Officer



My Bladder Cancer Story

Sharing personal stories about bladder cancer journeys helps others. Will you share your story about bladder cancer and BCAN?

bcan.org/stories



Women



Young Adults



Caregivers



Men

Getting the news

On January 10, 2020, Margo went in for her TURBT. The urologist explained that she had Stage 1, Grade 3 aggressive bladder cancer and he recommended BCG to treat the tumor.

A second opinion

At end of January, Margo decided to get a second opinion after mapping out the course of action with her doctor. After speaking with a new urologic oncologist, it was determined that Margo should have another TURBT with blue light technology just in case there was something that the first urologist did not see. None of the local hospitals in her hometown, Austin, Texas, had the blue light technology to perform this procedure so she began searching for yet another new doctor.

Margo discovered two potential options for blue light and treatment. One was MD Anderson Cancer Center in Houston, and the other was Baylor Scott and White Hospital, which has several locations in Texas.

Meeting Dr. Ashish Kamat

Margo had difficulty choosing, so she decided to submit her medical records to both hospitals. She heard back from MD Anderson first and set up her initial appointments.

Margo's appointment at MD Anderson was scheduled for March 2020 (at the onset of the COVID pandemic) with Dr. Ashish Kamat, a recognized expert in urologic oncology and a member of BCAN's Scientific Advisory Board.

Even looking at the same pathology report that her prior doctors had, Dr. Kamat saw something completely different, dramatically altering her diagnosis. Dr. Kamat found a second variant, a plasmacytoid. It is extremely rare and only occurs in 1% of bladder cancer cases. Then Margo heard the grave news: it always comes back, and when not treated, it is fatal.

Margo told BCAN, "Dr. Kamat looked at the same slides of the pathology, same data that my Austin doctors and pathologists did. The MD Anderson specialists saw something that the Austin doctors missed, and that was a second variant of the cancer



Margo (second from left) and her fellow bladder cancer patients at a panel at the 2022 Bladder Cancer Think Tank meeting.

in the bladder. I didn't know you could have two kinds of cancer in one place."

Margo stated that her body and mind went into "emergency management mode." She knew she had cancer but hearing that her type of cancer was potentially fatal was tremendous blow. Dr. Kamat continued by saying they needed to "do everything" because if they did not, Margo only had twelve to eighteen months to live.

Although stunned, Margo was determined. She said, "Now, we all have a reason that we take on this fight, and it's because of the people that we love who close to. In my case, I have been married to my husband for five years. I was 53 when I married him. So I said, 'We have to celebrate 50 years. We're not going to look good at 103, but we're going to get to celebrate our 50th anniversary.'"

The path forward

Dr. Kamat was prepared to do everything he could to ensure Margo survived. His treatment plan included chemotherapy, a radical cystectomy (bladder

Margo told her husband, "We have to celebrate 50 years [of marriage]. We're not going to look good at 103, but we're going to get to celebrate our 50th anniversary."

Continues on next page >

removal), and other potential treatments based upon ongoing clinical trials. He impressed upon a stunned Margo that they needed to start as soon as possible. The next day, Dr. Kamat performed another TURBT procedure on her and confirmed his diagnosis.

Margo spent four days and three nights in the hospital. Her chemo cycle lasted for 20 hours finishing with the “Red Devil,” doxorubicin, followed by 11 hours of hydration. She described leaving the hospital: “I basically just crawled to the car, laid down, slept on the way home, and then slept for another couple of days. I was feeling lousy.”

As she neared her second round of the chemo, COVID protocols at MD Anderson had become more stringent. She added, “My next round was two weeks after the first round, and by then there were no visitors allowed at all at MD Anderson. My husband couldn’t come in, nobody could. Unless you couldn’t walk on your own, you couldn’t have another soul with you. That was the case through the rest of my treatment, which was terrible.”

Margo also talked about the emotional aspect of not having her husband with her: “It’s already hard enough to go in for that treatment. Walking into a cancer hospital is not a good time. You’re glad you’re getting the treatment, but it’s hard. It’s emotionally hard. It’s physically hard.”

Bladder removal surgery

Margo had a radical cystectomy on June 10th, 2020. The surgeon also removed her cervix, her uterus, as well as some lymph nodes. Waking up from the operation was difficult for her. Margo told BCAN, “It is a very upsetting thing to wake up to. It’s very difficult to get used to not having your bladder.” She spent six days in the hospital after her surgery. She told BCAN, “There were times when I thought, I really I can’t do it. This just isn’t worth it. Let me go. It was the first time I’d ever felt like giving up.” Margo realized in

“I am eternally grateful for the bladder cancer community for their relentless search for the answers that bladder cancer patients desperately seek.”



**BLADDER
CANCER
MATTERS**
PODCAST

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BLADDER CANCER ADVOCACY NETWORK

Scan this code to listen to Part 1 of Margo’s Bladder Cancer Matters podcast interview with Rick Bangs.


that moment, fighting for her life required only that she survive. She now knew that she didn’t require the strength of a superhero to fight this cancer.

A positive outcome

As a result of her accurate diagnosis, aggressive treatment and radical cystectomy, Margo told BCAN that her story has a positive outcome. She said, “At a post-radical cystectomy appointment with Dr. Kamat, he came into the room and told me ‘You’re cancer free. It worked.’”

Margo’s deep gratitude

Thanks to Dr. Ashish Kamat and the wonderful support from Margo’s family, she is stronger than ever and has become a member of the BCAN family. Margo described Dr. Kamat as a “rock star,” and she credits him and bladder cancer research for saving her life. Margo said, “If I had not had access to some of the leading doctors in urologic oncology, I wouldn’t be here. If the leading doctors weren’t able to conduct research and collaborate with physicians about emerging discoveries for diagnosing and treating bladder cancer, I probably wouldn’t be here. I am eternally grateful for the bladder cancer community for their relentless search for the answers that bladder cancer patients desperately seek.”

She added, “I am so grateful for BCAN. I’ve gotten a lot of comfort from seeing other peoples’ stories, talking to other survivors. BCAN put me in touch with another woman who’d been through a similar treatment regimen to mine, and that was so comforting and helpful.” 

Adding to the BCAN Research Team

In August 2021 and recognizing the growth of BCAN's research portfolio, we welcomed a new employee to strengthen our research team, Valérie Aldana.


In her role, Valérie supports the implementation of BCAN's research and grant activities, including post-award management and tracking award deliverables and outcomes. She also works collaboratively in project management and oversight, supports new and existing funding initiatives and processes, award management and reporting, monitors programs and awards, as well as liaises with applicants and awardees.

Valérie's background

In her career, Valérie has worked on public health issues including oncology and health disparities. She also has additional experience in health equity while interning at Us Against Alzheimer's helping to improve the disease's stigma within minority populations. Prior to BCAN, Valérie served as a Senior Research Associate at the Sylvester Comprehensive Cancer



Valérie Aldana, MPH

Center in Miami, Florida, and as a Graduate Research Assistant at the Florida Cohort Study. She earned a Master's in Public Health. 



Walk to End Bladder Cancer

The 2023 Walks to End Bladder Cancer will be held virtually and in-person across the country. Our Walk raise much-needed funds that directly impact the lives of bladder cancer patients and those who love them. Register now at bcanwalk.org



For eight 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 eight consecutive years and we are proud to be good stewards of our donors' generous contributions.

Funding Research to Help Bladder Cancer Patients

For the last 13 years, BCAN has funded medical research designed to ease the burden of bladder cancer patients and families by investing in promising medical research. BCAN's research offerings include:

NEW IN 2022! CAREER DEVELOPMENT AWARD

.....

The Career Development Award will support researchers who have established an independent bladder cancer research program and successful career path.

Funding: \$250,000 over three years

NEW IN 2022! TRANSLATIONAL CLINICAL TRIAL AWARD

.....

This award will support patient-oriented research to transform bladder cancer care. It is designed to spark changes to the standard of care in bladder cancer, decrease overtreatment, and significantly impact patient outcomes.

Funding: Up to \$3 million over three years

RESEARCH INNOVATION AWARDS (RIAs)

.....

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

Funding: \$300,000 over two years

YOUNG INVESTIGATOR AWARDS

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Young Investigator Awards support 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.

Funding: \$50,000 for one year

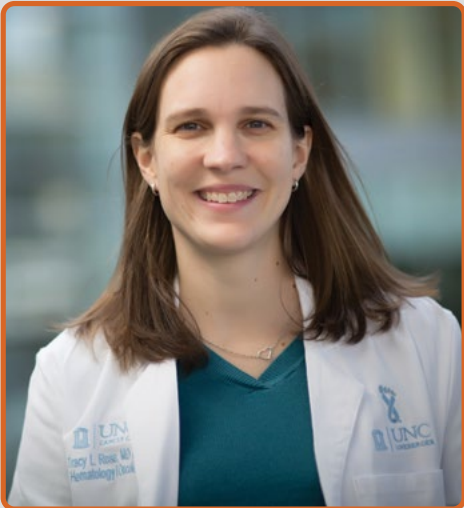
JOHN QUALE TRAVEL FELLOWSHIPS

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Since 2009, the John Quale Travel Fellowship Program has made it possible for early-career investigators interested in bladder cancer research to attend the annual Bladder Cancer Think Tank Meeting.

Funding: \$2,000 for travel and lodging

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



BCAN Introduces Two New Research Awards to Provide a Better Tomorrow for Patients

Bladder cancer research is critical to improve the prevention, detection and treatment of the disease and ensure that survivors live longer, better quality lives. Medical research also helps identify the causes of cancer and highlights improved methods of diagnosis and treatment. To help continue to propel research and create new possibilities, in August 2022, BCAN announced that it is funding two new bladder cancer research awards.

Translational Clinical Trial Award

The first award, announced during the annual Think Tank meeting held in August of 2022, is the first-ever Translational Clinical Trial Award (TCTA) that supports patient-oriented research to transform bladder cancer care. The award will provide a maximum of \$3 million in funding over 36 months to spark changes to the standard of care in bladder cancer, decrease overtreatment, and significantly impact patient outcomes.

This first-ever award is being funded through a generous grant from BCAN Board Member Duncan Alexander. Mr. Alexander has been a leader in the business community and has a long history of giving back through his philanthropic activities.

Through this award, BCAN seeks to bring enhanced urgency to the process of bladder cancer research and to support projects with novel approaches unlikely to be funded by industry or other sponsors. Rather than

Support for Bladder Cancer Patients

Sometimes, you just need to talk to someone who truly understands. BCAN's Survivor to Survivor program matches newly diagnosed bladder cancer patients with trained volunteers with similar backgrounds. If you are a bladder cancer patient and are looking to talk with someone for support, please visit bcan.org/S2S



To learn more about BCAN's grants and research funding opportunities, please visit bcan.org/research or scan this QR Code:

supporting basic research which results in general knowledge and understanding of a disease, this award will fund translational research and clinical trials. It will have a more immediate impact on bladder cancer treatments and approaches to medical care.

Applications will close on October 18, 2022 and TCTA award recipients will be announced in February 2023.


Career Development Award

In September 2022, BCAN began accepting applications for its first-ever Career Development Award (CDA). This award will support junior investigators who have yet to secure their first major study funding and aim to establish an independent bladder cancer research program. The CDA is a three-year grant totaling \$250,000 that will fund research that has direct relevance to bladder cancer.

The CDA will complement BCAN's other research awards and address the needs of investigators who are in the middle part of their careers. BCAN's Young Investigator Awards provide funding for early career professionals and its Research Innovation Award is presented to seasoned bladder cancer professionals.

Applications will close on October 18, 2022 and the awardee will be announced in January 2023.

Generosity fuels bladder cancer research

BCAN raises funds and awards to develop lifesaving treatments and improve patient outcomes. Our research awards would not be possible without the generosity of our wonderful donors and corporate partners. 

Bringing “Outside the Box” Thinking to Bladder Cancer Research

In July 2022, BCAN announced the 2022 recipients of its prestigious Bladder Cancer Research Innovation Awards. This year’s awardees are Tyler Curiel, MD, MPH, Gmelich Chair in Cancer Immunology Research at the Dartmouth-Hitchcock Clinic and John Sfakianos, MD, Assistant Professor of Urologic Oncology at the Icahn School of Medicine at Mount Sinai. These grants, which provide \$300,000 over two years, are part of the nearly \$7 million in research grants that BCAN has awarded to address important problems and critical barriers to progress as well as significant knowledge gaps in the field of bladder cancer research.

The need for research is critical: the National Cancer Institute estimates that there are more than 712,000 people living with bladder cancer in the United States, more than the populations of Vermont or Wyoming. Moreover, it is estimated that more than 81,000 people will receive a bladder cancer diagnosis in 2022 and upwards of 17,000 will not survive their disease.

“BCAN is delighted to provide funding for Dr. Sfakianos’s and Dr. Curiel’s novel research. These two awards fuel the type of high-risk, high-reward projects that can be tomorrow’s breakthroughs in bladder cancer research,” said Andrea Maddox-Smith, Chief Executive Officer of BCAN.

Dr. Curiel’s research project



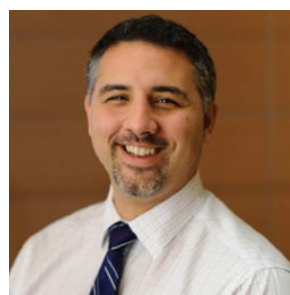
Tyler Curiel, MD, MPH

Dr. Curiel’s project aims to use a specially engineered version of Interleukin-2 (IL2), a protein that has great potential as a cancer immunotherapy, to stabilize the protein and direct its action towards immune cells that support tumor immunity. This will improve anti-cancer

immunity and avoid toxicities that typically occur after treatment. The researchers will use the novel engineered IL2 to treat local and metastatic bladder

cancer in mouse models and test tumor control, immunity and safety.

Dr. Sfakianos’s research project




John Sfakianos, MD

Dr. Sfakianos’s project will utilize two novel and complementary technologies, spatial transcriptomics and imaging mass cytometry in patient tumor samples before and after treatment with BCG to better understand BCG resistance. These novel technologies will enable

investigators to measure the gene and protein activity in patient tissue samples and map where the activity is occurring to provide more information about the role of the immune response in resistance to BCG in patients with non-muscle invasive bladder cancer.

Experts in their fields

Drs. Curiel and Sfakianos are recognized experts in their fields. Among other disciplines, Dr. Sfakianos’s research focuses on the approach to treating urothelial and prostate cancers in personalized medicine, including genomic analyses of tumors to predict risk and response to therapy. He has published more than 20 research articles in peer-reviewed publications, written book chapters on urothelial carcinoma and is a reviewer for the Journal of Urology and Urologic Oncology. Dr. Curiel’s work is in immune dysregulation in cancer as a means to understand cancer immunopathogenesis and develop novel cancer immunotherapies. He has authored or co-authored more than 15 peer-reviewed articles in prominent medical and research publications.

To learn more about how BCAN funds research to create a better tomorrow for patients, scan the QR code on page 8 or visit bcan.org/bcan-research/advanced-research 

Catching Up with Young Investigator Award Recipient Dr. Brendan Guercio

BCAN recently talked with Brendan Guercio, MD, a recipient of a 2021 BCAN Young Investigator Award (YIA). Dr. Guercio talked about the preliminary findings of the research project he conducted funded by BCAN.

Could you tell us a little about the research you conducted as part of your BCAN 2021 Young Investigator Award?

Using the award funding that BCAN generously provided, we started a study looking at patient dietary habits at the time that they were starting immunotherapy for either bladder cancer or upper tract urothelial cancer. We collected specimens so that we could look at characteristics of their gut bacteria.

Our hypothesis was that because gut bacteria have been shown to be a potentially important factor in determining people's responses to immunotherapy, their diet might also have significant impact on the bacteria that live in their gut. All of this is tied to how much patients benefit from immunotherapy.

Could you explain what gut bacteria is and why you think it's important to your research?

When bacteria come up in medicine, we think of them as a bad thing we have to treat with medicines. It turns out that there are lots of good bacteria that live in our guts that are just a normal part of our health. We try to make sure we have the right "bugs" living in our gut and also making sure that we are feeding them the right thing.

Although it's preliminary, what do you want bladder cancer patients to know about your research?

An early signal suggests that fiber may be helpful for people who are starting immunotherapy for bladder cancer. We know that it's a little too early to say if the signal we saw is valid, but we do know that generally, fiber is part of most healthy diets.

Do you think that the type of research you did is likely to be funded by other organizations?

I think that some sources are interested in funding



Brendan Guercio, MD, a genitourinary medical oncologist and recipient of a 2021 BCAN Young Investigator Award.

this type of research, but groups like BCAN are really the best and most interested. Sometimes it is hard to get funding for these sorts of studies because companies usually aren't going to make money from finding out that dietary habits can change cancer. There might be less funding out there from traditional sources like industry and pharmaceutical companies. Having organizations like BCAN that are motivated to really find out the answers that are important to patients is something that researchers like me definitely appreciate greatly.

What would you like bladder cancer patients and caregivers to know about the future of bladder cancer research?

I think I would want them to know that having and going through treatment for bladder cancer can be scary, but that there are a lot of exciting advances happening in the field right now and that have happened in the past few years. Most of all, I'd want them to be a little encouraged and hopeful about the improvements in bladder cancer treatment – some have already happened are others are likely to happen too. I also encourage patients, if they feel comfortable, to participate in research studies like ours or others because it's only by working with our patients that we make the most progress. This progress will hopefully help all bladder cancer patients in the future. **1**


Back and In Person! Think Tank 2022 Wrap Up

On August 3 - 5, 2022, BCAN hosted its 17th annual Bladder Cancer Think Tank (TT22). More than 200 people gathered in Denver, CO for three days of discussion and collaboration designed to improve outcomes for bladder cancer patients and those who love them.

After two years of virtual meetings, BCAN brought together a multidisciplinary group of clinicians, basic and social scientists, patient and caregiver advocates, and industry partners in person to improve the understanding and treatment of bladder cancer. The TT22 meeting featured exciting, collaborative discussions in two panel sessions, eleven unique breakout sessions, ten BCAN-sponsored researcher presentations, introduced a new class of eight John Quale Travel Fellows, and announced new BCAN-funded research initiatives.

A number of those sessions were recorded and for the first time, BCAN is pleased to provide access to those recordings to you. Scan the QR code to the right to watch any or all of the presentations or visit bcan.org/2022-bladder-cancer-think-tank. Available recordings include:

- BCAN Young Investigator Awardee Presentations
- Bladder Cancer Research Innovation Awardees' Presentations
- Next Generation of Trials in Non-Muscle Invasive Bladder Cancer
- Exposures to Environmental Contaminants as Important Risk Factors for Bladder Cancer
- Early Screening
- Artificial Intelligence
- Germline Genetics
- Identifying and Mobilizing Stakeholders and Allies for Health Equity in Bladder Cancer
- Sexual Intelligence in Bladder Cancer
- Advances in Organ-Sparing Management for Muscle-Invasive Bladder Cancer

The next Think Tank meeting will be held August 2-4, 2023 at the Capital Hilton in Washington, DC. 



Scan to view TT 22 presentations



BCAN co-founder Diane Zipursky Quale moderates a panel about incorporating the patient voice into bladder cancer care



Burles (Rusty) Johnson, MD, discusses his BCAN Young Investigator Award-funded research



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The free programs and resources that BCAN offers to bladder cancer patients and caregivers and the medical research we fund are the direct result of the unending generosity of our donors and corporate partners. Thank you.



Bladder Cancer Basics for the Newly Diagnosed

The newest edition of BCAN's handbook is 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.

bcan.org/handbook

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**



Exercise Your FreeWill