

A Letter from The Director

At the Johns Hopkins Greenberg Bladder Cancer Institute (JHGBCI), it feels like we are always lugging around heavy suitcases full of questions.

Questions about bladder cancer.

What causes it? How do we cure it? What should we be thinking about to serve our patients better?

As the poet Rainer Maria Rilke offered, *"...the point is, to live everything. Live the questions now. Perhaps you will then gradually, without noticing it, live along some distant day into the answer."* At the JHGBCI, we live questions about bladder cancer every day, and it's our hope that asking the right questions will finally lead to better answers.

Among the questions we've been pondering a lot lately are those specifically related to bladder cancer and women.

We know that women get bladder cancer less frequently than men, but women tend to present clinically with more aggressive disease, and sadly, often with poorer outcomes. Bladder cancer in women is more lethal, and we want to know why.

The question is really not just about women. There's something about bladder cancer: why is it more prevalent in men, yet more lethal in women? When we understand more about bladder cancer in women, we will understand more about bladder cancer in everyone. These are the fundamental questions we grapple with every day.

At the JHGBCI, we have made bladder cancer in women a research and clinical priority. We know we need to learn more, understand more,

and provide better treatment options for women.

In the clinical arena, in 2019, we are set to open what we think will be the very first Women's Bladder Cancer Clinic to be located at Sibley Hospital, a Johns Hopkins affiliate, in Washington DC. Staffed by urologic surgeon, Dr. Armine Smith and by medical oncologist Dr. Jean Hoffman-Censits, the Clinic will provide a home for women with bladder cancer, replete with a Bladder Cancer Multi-Disciplinary Clinic, and a robust research and clinical trials program.

In the research arena, Dr. Smith is studying the role of estrogen in bladder cancer, testing the hypothesis that may inhibit the development of less aggressive tumors while having no effect or even promoting the growth of the lethal ones. This research requires careful evaluation of clinical variables (numbers of pregnancies, estrogen supplementation) and experiments to define the effects of estrogen (and testosterone) on the growth of bladder cancer cells in laboratory models. Dr. Hoffman-Censits has a strong interest in immunotherapy. She also has a deep-seated curiosity about the microbiome and the overuse of antibiotics to treat urinary tract infections, which are often the cause of delayed diagnoses, especially in women. Does the overuse of antibiotics make immunotherapy less effective? These are the questions that will be visited in real time at the Women's Bladder Cancer Clinic at Sibley. And, as Dr. Hoffman-Censits notes, *"it's about time"* that we really took a hard look at bladder cancer in women, which has historically been under-researched and, perhaps, misunderstood.

In this newsletter, you'll also read about the remarkable Dr. Natasha Gupta, a urologic surgeon and fourth year urology resident, who has already made it her life's work to study and question how care is delivered to women with bladder cancer. She has undertaken a first-of-its-kind survey asking women who have undergone radical cystectomy questions about their pre-operative counseling, decision making, and outcomes following surgery. The much needed information obtained from our patients has already gleaned important information as to how we can better serve women with bladder cancer.

Additionally, Dr. Gupta is also conducting

a nationwide survey of urologic oncologists specializing in bladder cancer asking how they perform radical cystectomies in women. Her research focuses on organ preservation strategies that improve patient related outcomes with an emphasis on sexual health. Preliminary findings show that there is much work to be done to properly educate and improve care and support women with bladder cancer.

At the JHGBCI, we are lucky to have research partners around the world seeking answers to the same questions we grapple with. Recently, Professor Margaret Knowles, PhD, of the University of Leeds in the UK was awarded a second JHGBCI grant to study differences in the way genes are packaged into DNA in male and female urothelial cells. Preliminary findings reveal that there are important differences, which may explain why tumors in men and women behave so differently. Dr. Knowles' work - at the molecular level - proves that our hunch was right and that gender differences at the cellular level are real.

Suitcases full and brimming, we carry our questions around with us at the JHGBCI each and every day - to our laboratories and medical conferences, in our clinics and waiting rooms, and most of all, engaging our remarkable patients to help us find the answers.

Thank you for believing in our efforts, and helping us ask the right questions.

David J. McConkey, PhD

Director, Johns Hopkins Greenberg Bladder Cancer Institute

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It's About Time

Dr. Jean Hoffman-Censits' suitcase is also quite heavy: her questions specifically relate to women and bladder cancer.

Why do women typically present with more advanced bladder cancer and have a worse prognosis than men? Why are outcomes poorer, including a higher mortality rate for women? What role do hormones play? What can we be doing to diagnose women earlier and more accurately? How can we care for women with bladder cancer better?

"Women have a different journey when it comes to bladder cancer," offers Dr. Jean Hoff-

man-Censits, a medical oncologist at the JHGBCI and Co-Director of the Women's Bladder Cancer Center, a program supported at the East Baltimore campus, and with a

medical home at Sibley Hospital in Washington, DC. Many of her patients have complicated cancers of the bladder, ureter and renal pelvis; her clinical and research focus is on the understanding and treatment of these cancers.

With her team at the JHGBCI, and with her colleague Dr. Armine Smith, a urologic surgeon and Co-Director of the Johns Hopkins Women's Bladder Cancer Center, Dr. Hoffman-Censits is setting up what we think may be the first clinical and research center solely devoted to women with bladder cancer. "Women need a home center where we can focus our research and clinical efforts on women's bladder cancer, and allow for a place where women feel more comfortable being in a center where there are other women with the same disease who look just like them."

"It's time," says Dr. Jean Hoffman-Censits.

The Center's medical home at Sibley Hospital in DC, a Johns Hopkins affiliate, is currently

up and running, and offers the same quality of care as at Johns Hopkins in Baltimore, but closer to home for those who live in the DC area. The Center offers a Multi-Disciplinary Clinic model of care - all stakeholders who are involved in a patient's care are present to help guide treatment and decision making through their journey. Clinical trials will be offered and rigorous research, science, and discovery will be a part of the program.

"There is no clinical trial unique to women... yet," offers Dr. Hoffman-Censits. "At the same time we can ask questions about the differences in men and women with bladder cancer, which may lead to more targeted, gender specific trials over time."

We still offer excellent care for both women and

men with bladder cancer on our home campus in Baltimore; the new Sibley facility offers more options for all our patients. "Men with bladder cancer are most welcome at Sibley ... it's a program and not a location. All are welcome." We think it's about time.

"It's time."

- Dr. Jean Hoffman-Censits

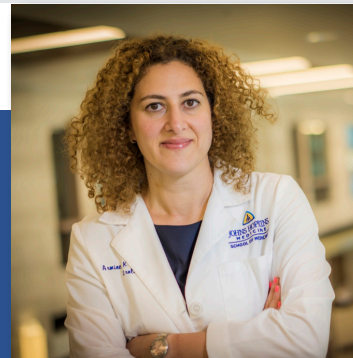
To make an appointment at the Women's Bladder Cancer Center, please contact:

Johns Hopkins Sibley Urology
5215 Loughboro Road NW, Suite 300
Washington, DC 20016

Appointments: 202-660-5561

Fax: 202-537-4440

To make an appointment at the Bladder Cancer Multidisciplinary Clinic at Johns Hopkins Hospital, please call 410-955-6100



About Dr. Armine Smith

Armine Smith, M.D. is an Assistant Professor of Urology at Johns Hopkins University and the Director of Johns Hopkins Urologic Oncology at Sibley Hospital. She completed her urologic residency at Cleveland Clinic, and urologic oncology fellowship at the National Cancer Institute.

Dr. Smith is highly trained in advanced urologic surgery, including both open and minimally invasive approach to oncologic diseases and the use of latest robotic technologies. Her clinical expertise spans a wide area of urologic malignancies with particular interest in bladder and kidney cancers. In bladder cancer surgery she specializes in complex urinary diversions, including continent orthotopic neobladder and continent catheterizable pouch techniques. In kidney cancer her particular area of expertise is partial nephrectomy, with the goal of oncologically-sound maximum nephron-sparing surgery.

Dr. Smith has lectured internationally and authored chapters on urothelial and kidney cancer. Her current research focuses on elucidating risk factors for development of bladder cancer and overcoming resistance to conventional therapy regimens, including development of personalized targeted therapies.



About Dr. Jean Hoffman-Censits

Jean Hoffman-Censits, M.D. is Assistant Professor of Oncology at the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins. She serves as the Co-Director of the Women's Bladder Cancer Center at Sibley Hospital in Washington, DC.

Dr. Hoffman-Censits completed her Residency and Chief Residency in Internal Medicine at Thomas Jefferson University Hospital, and Medical Oncology Fellowship at Fox Chase Cancer Center in Philadelphia. She is Board Certified in Medical Oncology. Dr. Hoffman-Censits is an expert in the field of genitourinary medical oncology. Her research interest is in the development of novel therapies for bladder and upper tract urothelial carcinoma. She also has interest in clinical trial enrollment strategies.

Asking All the Right Questions

Dr. Natasha Gupta, a fourth-year urology resident at the Johns Hopkins Brady Urological Institute, has been thinking a lot about bladder cancer in women. Dr. Gupta, with her unique experience as a surgeon-scientist who cares for patients with bladder cancer, has many questions about bladder cancer and women's experiences. As the recipient of a Johns Hopkins Greenberg Bladder Cancer Institute grant, she, under the mentorship of Dr. Trinity Bivalacqua, has single-handedly decided to find the answers by going right to the source: to patients, to hear what they have to say, and to listen.

Earlier this year, Dr. Gupta interviewed a cohort of female Johns Hopkins bladder cancer patients who had undergone a radical cystectomy. In phone interviews, she asked a series of questions, all with the goal of gleaning important information about their care and issues important to them - sensitive topics - seldom, if ever, discussed - such as body image, sexuality and intimacy, sexual dysfunction, the psychological burden of a cancer diagnosis, and more. In short, she asked the questions that should have been asked, but perhaps weren't, before. Dr. Gupta offers, "We want to learn how we can better address important concerns and quality of life issues among women with bladder cancer undergoing radical

cystectomy and further educate all urologists as to what can be improved upon, what conversations are needed."

In tandem with the patient surveys, Dr. Gupta has created a national questionnaire that has been electronically sent to approximately 700 urologists throughout the US through the SUO (Society of Urologic Oncology) and with the help of BCAN (Bladder Cancer Advocacy Network) to assess practice patterns and standards of care among urologists regarding sexual health counseling, surgical techniques, and nerve and organ sparing options for radical cystectomy in men and women. Her hunch is that urologists do not adequately counsel women about sexual health when making operative decisions. Asking urologists these important questions reveals what can be improved upon, and what patients want to hear about. Dr. Gupta's work is currently focusing on women, but, by starting the conversation, it can also be meaningful for male patients moving forward. She adds, "How can we deliver better care and educate our community to serve the needs of our patients better?"

We think that's a great question.



About Dr. Natasha Gupta

Natasha Gupta, M.D. is currently a fourth-year urology resident at the James Buchanan Brady Urological Institute at Johns Hopkins. Her research, under the guidance of Dr. Trinity Bivalacqua and with support from the Johns Hopkins Greenberg Bladder Cancer Institute, focuses on sexual health and dysfunction among women with bladder cancer undergoing radical cystectomy. Prior to residency, Dr. Gupta obtained a B.S. in biology at Duke University, attended the Johns Hopkins School of Medicine, and was a Doris Duke Clinical Research Fellow, which helped spark her interest in health outcomes research.

Please join

Mohamad E. Allaf, M.D.,

Theodore L. DeWeese, M.D.,

Jeffrey Kahn, Ph.D., M.P.H.,

William G. Nelson, M.D., Ph.D.,

Jean Hoffman-Censits, M.D.,

Armine K. Smith, M.D., and

Vered Stearns, M.D.

for a conversation about

BREAKTHROUGHS IN WOMEN'S CANCERS

Tuesday, February 5, 2019

5:00 - 7:30 pm

Naples, Florida

For more information, please contact
bladdercancer@jhmi.edu



BCAN Walk to End Bladder Cancer - Baltimore, MD

Date:

Saturday, May 11, 2019

Location:

Baltimore Campus
(University of Maryland)
1000 Hilltop Cir
Baltimore, MD 21250

Check-In: 9 AM

Walk: 10 AM

Registration & More Information:
<https://www.bcan.org/walk-to-end-bladder-cancer/>

HELP SUPPORT THE JHGBCI!

Your support of the JHGBCI is invaluable and helps serve those with bladder cancer. We hope that you will consider, among many needs, helping the JHGBCI underwrite the cost of our tumor sequencing program (not otherwise reimbursed). The cost of sequencing is approximately \$400 per sample, and contributes greatly to our understanding of bladder cancer and to the discovery of new treatment protocols.

We appreciate your partnership and belief in our mission.

To make an online gift to the Johns Hopkins Greenberg Bladder Cancer Institute, please Google:

JHGBCI CHARITABLE GIVING

Or click the image below:



For gifts of CASH, please make your check payable to Johns Hopkins and send it to the following address:

**The Brady Urological Institute
Development Office
600 North Wolfe Street, CMSC 130
Baltimore, MD 21287**

Please reference the Johns Hopkins Greenberg Bladder Cancer Institute or the faculty member to be supported by your gift on the memo line of the check.

Winter/Spring 2019 Bladder Cancer Support Group Meetings

January 3, 2019

Speaker: The Rev. Rhonda S. Cooper, M.Div., B.C.C. "Living with Cancer and the Role of Hope"

February 7, 2019

Speaker: Kevin Koo, M.D., M.P.H. "Kidney Stones and UTIs"

March 7, 2019

Speaker: Thomas J. Smith, M.D. "Pain management and palliative care"

April 4, 2019

Annual Product & Resource Fair

May 10, 2019

Special Patient Program & Luncheon

**Location: Johns Hopkins
Outpatient Center (JHOC),
2nd Floor, Rooms 2140-2150**

**Address: 601 N. Caroline Street
Baltimore, MD 21231**



The support group meets on the first Thursday of the month from 1:30-3:00 p.m.

Johns Hopkins Greenberg Bladder Cancer Institute
600 N. Wolfe Street | Park 2 | Baltimore, MD 21287

Request an appointment: (410) 955-6100

<https://www.hopkinsmedicine.org/greenberg-bladder-cancer-institute/>