



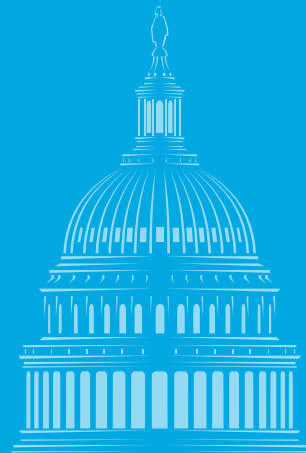
**ZERO**   
**PROSTATE CANCER**  
**SUMMIT**

FEBRUARY 25 - FEBRUARY 27, 2018

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#ZEROSummit2018



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# Welcome to the 2018 ZERO Prostate Cancer Summit

The journey to ZERO begins with you. You are the champions for the nearly three million American men and families fighting prostate cancer today; you are the heralds of inspirational stories from countless families who have fought courageously; and you are the heroes for the generation to come.

Ending prostate cancer takes passionate and informed leaders. Together, we have successfully fought for more than \$1.5B in prostate cancer research since ZERO was founded in 1996. The results of our shared work is remarkable – most treatments for advanced prostate cancer have spawned from the Department of Defense's Prostate Cancer Research Program as well as terrific breakthroughs aimed at deciphering aggressive tumors from indolent disease.

There are many challenges facing our nation and calling for solutions. But our challenges pale in comparison to those men who get up – battling prostate cancer, facing financial troubles, and strapping on their boots to power through work each day. For these families, our cause means defending patient rights, widening access to care, and providing support in navigating the challenges in their cancer journeys.

While much of our work is focused on improving research outcomes, reducing prostate cancer deaths requires a commitment to education, testing, and health programs that cut through barriers to care. Thanks to your support, we're providing more solutions than ever before to patients who struggle with their care.

As we move forward, we are excited to see how the landmark discoveries and health care improvements we help create today will better the lives of patients and their families tomorrow. Our shared, cause-driven passion will light our journey and blaze a path to the end of prostate cancer.

With Deep Gratitude,

Jamie Bearse  
President and CEO  
ZERO – The End of Prostate Cancer



## AGENDA

### SUNDAY, FEBRUARY 25

12:00 p.m. – 4:00 p.m.

#### Registration

4:00 p.m. – 5:30 p.m.

#### Welcome

Jamie Bearse, President and CEO, ZERO

Jefferson  
Ballroom I & II

#### Advocate-Led Roundtables

5:30 p.m. – 7:00 p.m.

#### Dinner (On your own)

#### Optional Entertainment

7:00 p.m. – 7:10 p.m.

#### Laughing with Cancer

Ian Mair, Author, *Laughing with Cancer: A Prostate Cancer Comedy*

7:15 p.m. – 9:00 p.m.

#### Screening and Q&A:

#### **The Silent Killer: Prostate Cancer in the African American Community**

Landi Maduro, Director

### MONDAY FEBRUARY 26

7:30 a.m. – 8:00 a.m.

#### Breakfast

8:00 a.m. – 9:40 a.m.

#### Counting Down to ZERO: Advocacy's Impact on Prostate Cancer

Jamie Bearse, President and CEO, ZERO

#### Policy Agenda Review

Drew Saelens, MBA, MS, Vice President of Government Relations and Patient Advocacy, ZERO

#### Research Highlights from the PCRP and NIH

Alicia Morgans, MD, MPH, Medical Advisory Board Chair, ZERO; The Feinberg School of Medicine, Northwestern University  
Melissa Cunningham, Prostate Cancer Research Program, Congressionally-Directed Medical Research Programs, Department of Defense  
William Dahut, MD, Head, Prostate Cancer Research Section, Center for Cancer Research, National Institutes of Health  
Jim Wilhelmsen, Patient Peer-Reviewer for the Prostate Cancer Research Program, Congressionally-Directed Medical Research Programs

#### WHO WE'RE FIGHTING FOR

9:40 a.m. – 10:00 a.m.

#### Patient Speakers

Burt Watson, Prostate Cancer Survivor, Executive Vice President of Operations, Alliance MMA  
Robert Ginyard, Board of Directors, ZERO

10:00 a.m. – 10:15 a.m.

#### Keynote Speaker

Glenn Consor, Prostate Cancer Survivor, Play-by-Play Personality, Washington Wizards

10:15 a.m. – 10:30 a.m.

#### Advocate Coffee Break

## AGENDA

### MONDAY, FEBRUARY 26

#### WHAT WE'RE FIGHTING FOR

10:30 a.m. – 11:30 a.m.

#### Promising Drug Therapy Data from 2017 for High-Risk Groups and Earlier Use Immunotherapy and African Americans

Stephen Freedland, MD, Associate Director, Faculty Development Samuel Oschin Comprehensive Cancer Institute, Co-Director, Cancer Genetics and Prevention Program, Director, Center for Integrated Research in Cancer and Lifestyle, Professor, Surgery, Warschaw Robertson Law Families Chair in Prostate Cancer

#### Earlier Use of Drug Therapy in Prostate Cancer

Nancy Dawson, MD, Director of the Genitourinary Medical Oncology Program and Clinical Research Management Office; and director of the Clinical Research and Prostate Cancer Treatment and Research Center, MedStar Georgetown University Hospital and the Georgetown University Medical Center

11:30 a.m. – 12:00 p.m.

#### Break for Lunch Buffet

12:00 p.m. – 2:05 p.m.

#### Working Lunch: Biomarkers

#### New Guidelines on Genetic Testing and Counseling

Veda Giri, MD, Director of Cancer Risk Assessment and Clinical Cancer Genetics in the Department of Medical Oncology and member of the Prostate Cancer Program at the Sidney Kimmel Cancer Center and lead author on Genetic Testing and Genetic Counseling guidance

#### Differences Between Genetics and Genomics and Use of Each in Prostate Cancer

Karen Copeland, Board-Certified Genetic Counselor, Medical Science Liaison, Myriad Genetics  
John Ryan, Hereditary Cancer Patient  
Deb Davison, Associate Medical Director, Genomic Health  
Jim Green, Prostate Cancer Survivor

#### Sorting Out Genomic Testing for Prostate Cancer

Leonard Gomella, MD, FACS, Bernard W. Godwin, Jr. Professor of Prostate Cancer, Chairman, Department of Urology, Clinical Director, Jefferson Kimmel Cancer Center Network, Senior Director for Clinical Affairs, Jefferson Kimmel Cancer Center

2:15 p.m. – 3:15 p.m.

#### Breakout Sessions

Crystal III

#### African-Americans' Disparity in Screening, Surveillance, and Care

Kelvin Moses, MD, PhD, FACS, Vanderbilt-Ingram Cancer Center Medical Advisory Board Member, ZERO  
Burt Watson, Prostate Cancer Survivor, Executive Vice President of Operations, Alliance MMA  
Robert Ginyard, Board of Directors, ZERO  
Grace Mishkin, MPH, Public Health Analyst, Cancer Therapy Evaluation Program, National Institutes of Health

Crystal V

#### How to Effectively Engage Your Elected Officials and Advocate in Your Community

Tyrone McClain, Pfizer Oncology, Former District Director, Congressman James Himes (CT-4)  
Steve Hentzen, Co-Founder, The Prostate Network  
Don Slaght, Champion Chair, New Jersey

Crystal VI

#### The Hidden Side of Prostate Cancer: The Side Effects No One Wants to Talk About

Phil Shulka, Recovery Coach, Chesapeake Urology  
Alicia Morgans, MD, MPH, Medical Advisory Board Chair, ZERO; The Feinberg School of Medicine, Northwestern University  
Meredith Morgan, MSN, Urology Oncology Clinic, University of Michigan Comprehensive Cancer Center, Medical Advisory Board, ZERO

## AGENDA

### MONDAY, FEBRUARY 26

3:30 p.m. – 4:30 p.m. **Repeat Breakouts**

#### **HOW WE'RE FIGHTING**

4:35 p.m. – 5:45 p.m. **Remarks by Congressman Mo Brooks (AL-5)**

##### **Policy Agenda Recap/Reminder**

Drew Saelens, MBA, MS, Vice President of Government Relations & Patient Advocacy, ZERO

##### **How to Tell Your Story to Congress**

Jamie Bearse, President and CEO, ZERO

Suzanne M. Schlernitzauer, HIA, FLMI, ACS, ARA, AIAA, AIRC

##### **What to Expect in Your Meetings and Meeting Role Play**

Susan Sweat, Senior Vice President, Cornerstone Government Affairs

Patrick Ronk, Associate, Cornerstone Government Affairs

##### **Meeting Schedules, Q&A**

5:45 p.m. – 6:00 p.m. **Closing Remarks and Adjourn**

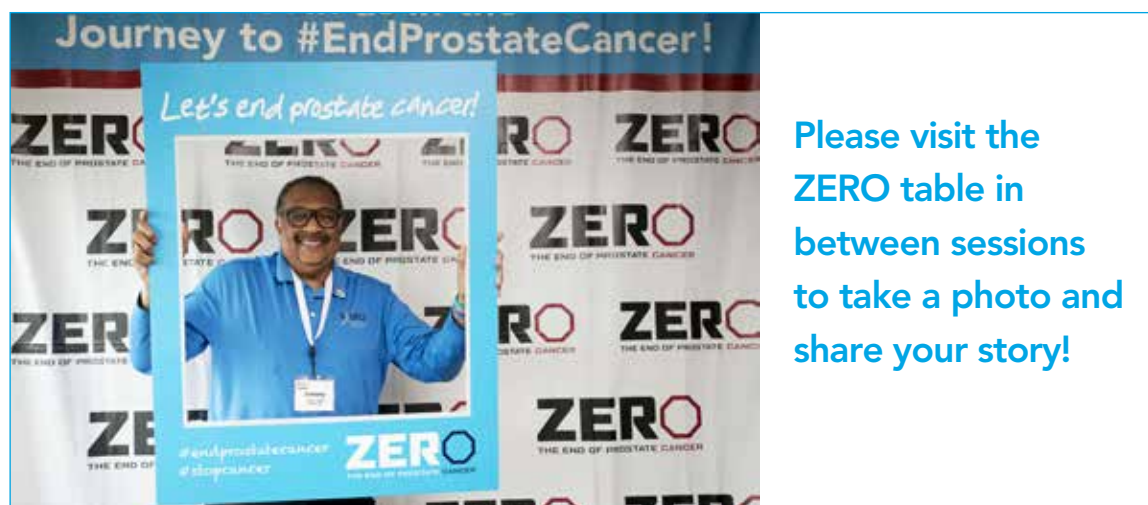
Jamie Bearse, CEO, ZERO

### TUESDAY, FEBRUARY 27

7:00 a.m. – 8:00 a.m. **Breakfast, Schedules, and Questions**

8:00 a.m. – 5:00 p.m. **Advocates Offsite for Hill Meetings**

5:30 p.m. – 7:30 p.m. **Congressional Reception** – 2075 Rayburn House Office Building  
Remarks from Congressman Peter King (NY-2) and  
Congressman Roger Williams (TX-25)



## BREAKOUT GROUP TOPICS

### **African-Americans' Disparity in Screening, Surveillance, and Care**

When the United States Preventive Services Task Force (USPSTF) released their updated draft recommendation for the PSA screening, they specifically noted the lack of PSA data related to African-Americans, thus preventing them from making a carve out in their draft recommendation. We are also seeing a similar pattern in African-American enrollment in clinical trials as well as studies relating to the potential use of active surveillance as a treatment option. This panel of experts will discuss this and what can be done to help decrease these disparities.

### **How to Effectively Engage Your Elected Officials and Advocate in Your Community**

Led by a panel of advocates and experts who have put their passion into action, we will focus on what you can do to stay involved once you leave the #ZEROSummit2018. There are many different ways to begin a dialogue in your local community and this panel will provide tools and examples.

### **The Hidden Side of Prostate Cancer: The Side Effects No One Wants to Talk About**

Many side effects from prostate cancer are difficult to deal with and discuss. However, issues like depression and anxiety are far too common when battling the disease and too few patients ever ask for help. Even issues like fogginess, falls, or dizzy spells can be symptoms of prostate cancer while typical side effects like erectile dysfunction and urinary incontinence can be mistaken for normal aging. Join us to learn how to spot them and overcome them.

## SPEAKERS AND MODERATORS

### **Glenn Consor**

Glenn Consor is currently in his eleventh season as the color analyst and post-game show host for the Washington Wizards. Diagnosed with prostate cancer just a few years ago, Glenn had a unique experience dealing with a prostate cancer diagnosis while working in the NBA, a community made up of mostly men. Glenn attributes his early diagnosis and treatment to early detection and uses his platform as a sports broadcaster to advocate for cancer awareness and early detection.

### **Karen Copeland**

Karen Copeland, a board-certified Genetic Counselor, has worked in the field of human genetics for over 33 years in a variety of settings including academic centers, hospital-based programs and private companies. She has been with Myriad Genetics, Inc. for more than 13 years where she provided training, education and support to genetic counselors, nurses and physicians for hereditary cancer risk assessment. Karen currently is a Medical Science Liaison in the Urology Business Unit focusing on molecular markers and hereditary risk in prostate cancer.

### **Melissa Cunningham, PhD**

Dr. Cunningham joined the DOD's Congressionally Directed Medical Research Programs (CDMRP) as a Science Officer in 2010 where she coordinated and managed a large portfolio of active research projects for the PCRP, including management of the high-profile Prostate Cancer Clinical Trials Consortium (PCCTC). Dr. Cunningham assumed the leadership of the PCRP as Program Manager in 2014. She is responsible for executing the entire PCRP program life cycle, including investment strategy, program announcement development, proposal review, funding of awards, and analysis of PCRP accomplishments and effectiveness.

### **William Dahut, MD**

Dr. William Dahut is the head of the Prostate Cancer Clinical Research Section at the National Cancer Institute (NCI) at the National Institutes of Health (NIH). Dr. Dahut received his M.D. from Georgetown University in Washington, D.C. Dr. Dahut became Chief of the GU/GYN Clinical Research Section in the Medical Oncology Clinical Research Unit in 2002, where his primary research interest has been in the development of novel therapeutic strategies for the treatment of adenocarcinoma of the prostate.

## SPEAKERS AND MODERATORS

### **Deborah Davison, DNP, CRNP**

Deborah Davison is an Associate Director, U.S. Medical Affairs for Genomic Health, Inc. Deborah is a nurse practitioner with over 25 years of experience in oncology. In addition to clinical practice, she also worked in oncology clinical research at the National Surgical Adjuvant Breast and Bowel Project (NSABP) and has held a variety of faculty positions. She has a doctorate in nursing from Chatham University and received her nurse practitioner training at the University of Pittsburgh.

### **Nancy Dawson, MD**

A renowned expert in urologic cancer, Nancy Ann Dawson, MD, holds dual appointments at MedStar Georgetown University Hospital and the Georgetown University Medical Center, including the William M. Scholl Professor of Medicine and Oncology; director of the Genitourinary Medical Oncology Program and Clinical Research Management Office; and director of the Clinical Research and Prostate Cancer Treatment and Research Center. Her medical career includes clinical care and research in urologic cancers at Walter Reed Army Medical Center and at the University of Maryland School of Medicine.

### **Stephen Freedland, MD**

Dr. Freedland is Director of the Center for Integrated Research in Cancer and Lifestyle, co-director of the Cancer Genetics and Prevention Program and associate director for Faculty Development at the Samuel Oschin Comprehensive Cancer Institute. He is a faculty physician in the Division of Urology at the Cedars-Sinai Department of Surgery. Freedland's clinical expertise focuses on urological diseases, particularly benign prostatic hyperplasia and prostate cancer.

### **Robert Ginyard**

An entrepreneur, former banker, and marketing director, Robert is a veteran Summit speaker who promotes prostate cancer awareness and overall good health. He is a prostate cancer survivor and board member at ZERO who works to raise awareness through media interviews and outreach with his new Dream it. Believe it. Do it. Be it. (DiBi DiBi) campaign.

### **Veda Giri, MD**

Dr. Giri is the lead author of the "Role of Genetic Testing for Inherited Prostate Cancer Risk: Philadelphia Prostate Cancer Consensus Conference 2017." She is the Director of Cancer Risk Assessment and Clinical Cancer Genetics at Thomas Jefferson University (TJ) where her role will be to lead an integrated and comprehensive effort in inherited cancer risk assessment and conduct studies focused on genetic evaluation of cancer risk. She is also an Associate Professor in Medical Oncology and Cancer Biology at Sidney Kimmel Cancer Center at TJ. She is a medical oncologist with a clinical and research interest in inherited cancer risk assessment.

### **Leonard Gomella, MD, FACS**

Dr. Leonard Gomella is the Bernard W. Godwin, Jr. Professor of Prostate Cancer and Chairman of the Department of Urology at Jefferson Medical College. Dr. Gomella is involved in both basic science and clinical research in the development of new diagnostic techniques and treatments for prostate, bladder and kidney cancer through the Thomas Jefferson University Kimmel Cancer Center, where he was named Clinical Director in 2008.

### **Jim Green**

Jim Green is a prostate cancer survivor from Colorado who utilized genomic testing to help him confirm that active surveillance was the best path for him. Jim advocates for men to gain as much information as possible to make a well-informed decision on their treatment path.

## SPEAKERS AND MODERATORS

### **Steve Hentzen**

Steve Hentzen is the Chairman and a co-founder of the Prostate Network, a support group based out of Kansas City, KS. A second year Summit attendee, Steve is a member of the Kansas Cancer Partnership, Missouri Cancer Consortium, and he is a member of the Patient Advisory Board at the University of Kansas Cancer Center.

### **Landi Maduro**

Landi Maduro is a producer and writer, known for the documentary, "The Silent Killer: Prostate Cancer in the African American Community." About six months into the making of the film, Landi's father was diagnosed with prostate cancer. She credits the knowledge and research she gained while creating the film for helping her father choose his treatment. Landi has made it her mission "to leave no stone unturned exposing [prostate cancer as a] culturally taboo subject and bringing to light the deadly consequences of avoiding exams."

### **Ian Mair**

Ian Mair is a prostate cancer survivor as well as the author of "Laughing With Cancer: A Prostate Cancer Comedy." Ian used humor to lighten moments with others and to soothe his own concerns and trepidations during his diagnosis, biopsy, and subsequent surgery. Ian advocates for more awareness using humor to break down the barriers that often prevent men from talking about prostate cancer.

### **Tyrone McClain**

Tyrone McClain is Director, Public Affairs for Oncology at Pfizer. In this role, McClain is responsible for developing policy, advocacy, and public affairs strategies to advance development of and access to treatments in lung and prostate cancer. McClain brings a wealth of knowledge and expertise to Pfizer with more than a decade of government and political experience, holding leadership roles under elected officials on both the local and federal level. McClain joined Pfizer in 2017, following a four-year stint in the United States House of Representatives as the District Director for Congressman Jim Himes, who represents Connecticut's 4th congressional district. McClain attended Wheaton College in Norton, Massachusetts where he graduated in 2004 with a Bachelor of Arts in Sociology.

### **Grace Mishkin, MPH**

Grace is a Public Health Analyst at the National Cancer Institute's (NCI's) Cancer Therapy Evaluation Program (CTEP). She provides operational support for NCI's National Clinical Trials Network and coordinates several cross-cutting projects around clinical trials. Areas of focus include clinical trial accrual, representation of underserved populations in research, research biospecimen and data availability and infrastructure, and systems evaluation and improvement. Grace came to NCI as a Presidential Management Fellow. Grace received her BA from Harvard College and her Master's of Public Health from Emory's Rollins School of Public Health.

### **Meredith Morgan, MSN, NP**

Meredith Morgan, ACNP-BC, is a Urologic Oncology Nurse Practitioner at Weill Cornell Medical College/New York-Presbyterian Hospital. She leads a survivorship program at Cornell to follow patients who have been treated for a urologic cancer and are in remission. She specializes in non-surgical treatment options for post-prostatectomy erectile dysfunction.

### **Alicia Morgans, MD, MPH**

Dr. Morgans is an Assistant Professor of Medicine in the Division of Hematology/Oncology at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University in Chicago, IL. She specializes in the treatment of genitourinary cancers including prostate, bladder, testis and penile cancers, and she has a special interest in advanced prostate cancer. Dr. Morgans is actively involved in medical research and her current research projects are looking at the side effects of cancer treatment including the prevention, diagnosis of, and treatment of these side effects.

## SPEAKERS AND MODERATORS

### **Kelvin Moses, MD, MPH**

Dr. Moses is Assistant Professor of Urologic Surgery at Vanderbilt University Medical Center and Chief of Urology at Nashville General Hospital in Nashville, TN. He received his training at Emory University, and completed a fellowship at Memorial Sloan-Kettering Cancer Center where he served as Chief Administrative Fellow. Clinically, he focuses on advanced prostate cancer care (metastatic and castrate-resistant disease), as well as renal, bladder, and testicular cancer.

### **John Ryan**

John Ryan is the Vice President of Operations for Hereditary Cancer at Myriad Genetics. He currently leads a team of over 200 scientists, directly involved with Hereditary Cancer testing. As a Hereditary Cancer patient speaker having an extensive family history of both Hereditary Cancer and experience with Hereditary Cancer testing, John will share his experience from the perspective of a patient.

### **Don Slaght**

Don Slaght is a local business owner in the New Jersey shore area who was diagnosed with prostate cancer in 2016. Now a survivor coming to his second Summit, Don is the ZERO New Jersey Champion Chair where he actively works to advance ZERO's mission in his home state.

### **Suzanne M. Schlernitzauer, HIA, FLMI, ACS, ARA, AIAA, AIRC**

Susie Schlernitzauer is a local business owner in Miami, Florida as well as Director of the annual ZERO Prostate Cancer Run/Walk - Miami. A stalwart Summit advocate, Susie works tirelessly to raise awareness and money to end prostate cancer in her local community.

### **Phil Shulka**

Phil Shulka is a prostate cancer survivor and a ZERO Prostate Cancer Summit veteran. As Recovery Coach for Chesapeake Urology Associates (CUA), Phil provides one-on-one peer support for CUA patients throughout their cancer treatment.

### **Burt Watson**

Burt Watson is a prostate cancer survivor who has served in a host of positions with some of boxing and MMA's most recognized names for the past forty years. As a consultant, advisor, promoter and event coordinator, Burt commands a wealth of knowledge unparalleled in both industries. He has coordinated and been a part of some of the most unforgettable events in Boxing, UFC, and MMA. Diagnosed with prostate cancer a year ago, Burt has partnered with ZERO to make sure that more men get tested and understand their risks.

### **Jim Wilhelmsen**

Jim Wilhelmsen is a prostate cancer advocate and patient. Based in Arizona, he and his wife Venetia share his story to educate men on early detection. Jim and Venetia frequently represent ZERO at health fairs as well as charitable giving events in their local community.

## In Memorium

Dedicated to the memory of the beloved members of our community we lost to prostate cancer this past year.

*Ronald Becker*

*Darrell Blankenship*

*Edward Kent Blough*

*George Bondarenko*

*Michael Anthony Brocato, Sr.*

*John K. Class, Jr.*

*James Diulus*

*Gary Dunn*

*Russell Faulk*

*Robert Fischer, Jr.*

*James Foley*

*Walter "Tom" Hawk*

*Fred Hoffman*

*Tom Huch*

*Jeffrey Kramsky*

*James Leggieri*

*Dr. Mitchell Levinson*

*James Nathan Mills, Jr.*

*William B. Manning*

*Denny Moore*

*Ronald Pliske*

*David Rifkind*

*Dr. Dennis Saacks*

*Gil Seibel*

*Igor Shpitsberg*

*R. John Therres*

*Deacon Vernon Thompson, Jr.*

*Ramon Torrandell*

*Jerry Woolverton*

## ABOUT ZERO

ZERO — The End of Prostate Cancer is the leading national nonprofit with the mission to end prostate cancer. ZERO advances research, improves the lives of men and families, and inspires action. We're building Generation ZERO, the first generation of men free from prostate cancer, through our national run/walk series, education and patient support programs, and grassroots advocacy. ZERO is a 501(c)(3) philanthropic organization, accredited by the Better Business Bureau, with regional chapters across the country. We dedicate 84 cents of every dollar to research and programs. For more information, visit [www.zerocancer.org](http://www.zerocancer.org).



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