Welcome

Pre-Summit Logistics and Policy Webinar
February 11, 2020
Agenda

- Welcome
- Preparation for your trip to DC
- Schedule
- Logistics
- Legislative Priorities Overview

REMEMBER:
If you have a question during this webinar there is a **100% chance** someone else in the group has the same question, so ask away!!
Welcome

We are excited to have you!

• There is a new location and a new format.
• We have nearly 250 attendees coming from around the country (even more than last year)
• So many people that our hotel room block is FULL!
• A recording of this webinar, as well as the presentation, will be made available on the Summit Website.
Frequently Asked Questions: How Should I Dress for the Summit?

- **Sunday**
  - Casual for travel and registration
  - Festive Blue for Bold for Blue Awards
- **Monday**
  - Business Casual
  - Jeans are fine
- **Tuesday (Hill Visits)**
  - We ask our advocates to wear clean and appropriate professional attire (suits, dress pants; shirts with ties; dresses; skirts and blouses; etc.)
  - No printed t-shirts or jeans
  - Comfortable shoes
  - Remember: you represent ZERO
Frequently Asked Question:
What is the Weather Going to be like in DC?

• Average high temperature in Washington, D.C. in February is 47 degrees
• Average low temperature is 31 degrees
• Rain and snow showers are common
• Please dress prepared for the typical weather
• Bring an umbrella
Sunday, February 23

12:00 pm – 4:00 pm  Registration
5:00 pm - 7:00 pm  Dinner on Own
7:00 pm – 9:30 pm  Bold for Blue Awards
Monday, February 24 - Morning

7:00 am – 7:30 am  Breakfast
7:30 am – 12:00 pm  Plenary
8:00 am – 9:00 am  Keynote – Dr. Mark Moyad
12:00 pm – 12:30 pm  Lunch Buffet
12:30 pm – 1:00 pm  Prostate Cancer Research Program
Monday, February 24 - Afternoon

• Advocacy Track 1-5 pm
  o Prep for Capitol Hill Meetings
• Education Track 1-5 pm
  o 12 Breakout Sessions
• After-hours Sessions 5-7pm

Q: Do we choose which breakout sessions we attend?
  o A: You are welcome to go to any breakout session you would like. You may also leave a breakout session to go to another one.
Tuesday, February 25

- Advocacy Track 7am-5pm
  - Capitol Hill Meetings
- Education Track 8am-5pm
  - Integrative Medicine and Caregiver Focus
- Closing Reception 6-7:30 pm
Transportation to Gaylord

- Address
  - Gaylord National Resort & Convention Center
    165 Waterfront Street, National Harbor, MD 20745
- Accessible via taxi and rideshare options
- Public transportation via WMATA NH1 and NH2
Hotel

- Hotel will collect credit card information from all attendees for incidentals
- Hotel will also collect credit card information for non-scholarship advocates paying for their own room
- Roommate assignments are subject to change but we will let you know
- Discount parking tickets will be available from the ZERO registration table. Email summit@zerocancer.org to make a request in advance.
Participation Opportunities

Video Shoot
  o  Chemotherapy Patients

Focus Group
  o  Insurance consumers

Email summit@zerocancer.org to express interest.
Questions?

2020

ZERO PROSTATE CANCER SUMMIT
EDUCATE  ADVOCATE  CELEBRATE

ZEROCANCER.ORG
• As a ZERO advocate, you are an ambassador of ZERO and thus your conduct will reflect whether congressional staffers wish to meet with us in the future

• Please consider every meeting on your schedule to be mandatory unless otherwise specified

• Please arrive to all of your scheduled congressional meetings prepared, on time, and dressed in professional attire

• Please refrain from sharing your personal political opinions during your meetings on Capitol Hill
What Else Should I Bring to the Hill?

- Reminder: Comfortable Shoes!!
- Contact information for follow up
  – business cards are good
Logistics

Transportation to Capitol Hill

ZERO will provide bus transportation on Tuesday February 25th for advocates from the hotel to the Capitol in the morning and to the hotel in the evening for the evening reception.

**Morning Departures:** 7:00 and 8:00 am

**Afternoon Departures:** 4:30 and 5:30 pm
Q: I have not received my airline itinerary. Have they been emailed?
A: For scholarship attendees, airline itineraries and confirmations should have been emailed to you via Travel Partners when you selected your flights. If you cannot locate your information please contact summit@zerocancer.org.

Q: Some airlines charge for bags is this our responsibility?
A: It is not our policy to cover bag fees from the airlines. If it causes a hardship however, please reach out to summit@zerocancer.org.

Q: If we are driving, can we get a parking pass?
A: Yes, discount parking passes will be available on site at the Summit registration desk. Email summit@zerocancer.org to make a request in advance.

Q: When will I receive the pre-arrival packet?
A: Pre-arrival packets will be shared later this week and will also be printed and ready for everyone when they check in on Sunday afternoon/Monday morning.
Q: What about security, is there anything we shouldn't bring?
A: In the House and Senate office buildings you may not bring weapons of any kind, such as knives or firearms. If you go into the Capitol Building you are also not allowed to bring any food or liquids.

Q: About how many meetings can we expect to complete on Tuesday?
A: On average, each group will have 4-5 meetings.

Q: Can we get extra information packages to drop off at the offices that we cannot visit?
A: Definitely, let us know on Monday during training or Tuesday morning.
Hill Visit FAQs

Q: Will we be given notes on the Members of Congress like which committees they are on or what their current stance is on proposals?
A: Yes, on Monday afternoon you will be given bios and information on the members you will be meeting with the following day.

Q: Will there be plenty of ZERO "swag" we can get? I'd love a lapel pin for my jacket.
A: ZERO “swag” will be in your arrival bags at the ZERO registration desk. You will also receive a special ZERO button for the Hill visits.

Q: Is it ok to leave our own personal business cards with the congressional staffers?
A: Definitely, you should leave your personal business cards with them to start a dialogue after you leave DC.
Hill Visit FAQs

Q: Are there multiple advocates at each meeting?
A: Yes, advocates will be put into groups and you will be going around with them to meetings.

Q: Duration of each meeting?
A: Each meeting will run roughly 20-30 minutes each.

Q: Is there a Summit hashtag to help us see each other's posts?
A: #ZEROSSummit2020
Legislative Priorities

• Protecting and Growing Federal Funding for Prostate Cancer Research
  – Prostate Cancer Research Program (PCRP) at the Department of Defense (DoD)
  – Prostate Cancer outreach, surveillance and education funding at the Centers for Disease Control and Prevention (CDC)
• Elimination of PSA copays for high-risk men
  – The Affordable Care Act (ACA or ObamaCare) tied coverage of PSA screening to USPSTF recommendations
  – Reps. Rush (D-IL) & Bucshon (R-IN) have introduced legislation – the PSA 4 Him Act (HR 5200) and remove copays for African-American men and men with a family history of disease
• Development of a clinical pathway at the VA
  – The VA offers uneven care for prostate cancer
  – Rep. Dunn (R-FL) is working on legislation that would require the VA to have a clinical pathway established for prostate cancer treatment
Protecting and Growing

Protect the Prostate Cancer Research Program (PCRP) at the Department of Defense (DoD)
Federal Funding for Prostate Cancer Research at the DoD

- The Prostate Cancer Research Program (PCRP) is part of the Congressionally Directed Medical Research Programs (CDMRP)
- Their mission is to fund research that will lead to the elimination of death from prostate cancer and enhance the well-being of men experiencing the impact of the disease.
- Started in 1997 with $45M
- Total appropriation through FY 2019 is $1.93B
- Received increases of over $30M in appropriations in the last four years thanks to ZERO advocates
- Funding from the PCRP has developed 3 new treatments for advanced disease in the last 9 years (ZYTIGA®, XTANDI®, XGEVA®)
Legislative Priorities

Because of YOU!

PCRP Funding History

Appropriations in Millions

Fiscal Year


0 20 40 60 80 100 120
Legislative Priorities

- Some outside groups and Members of Congress believe the CDMRP is a duplicative or wasteful program that should be eliminated
  - One of the most outspoken Members on this issue was Senator John McCain (R-AZ), Chairman of the Senate Armed Services Committee, Sen. McCain did not believe that the DoD should be doing biomedical research.
- In 2016, Sen. McCain included two provisions in the FY 2017 National Defense Authorization Act (NDAA), the yearly bill that dictates our national defense priorities, designed to eliminate many of the programs at the CDMRP
  - ZERO teamed up with multiple other patient advocacy groups to defeat these provisions on the Senate floor
- In late 2017, McCain added language again in the FY 2018 NDAA.
  - Unfortunately, votes were not allowed on the bill when it was considered by the Senate (this was due to an unrelated policy issue)
  - ZERO took the lead with other partner organizations within a medical research coalition to successfully defeat these provisions during House-Senate conference negotiations
- Senators Durbin and Blunt (R-MO) led a letter that garnered 53 signatures opposing the language
  - A similar letter, lead by Representatives Costello (R-PA), King, Bishop, & Loebsack (D-IA) attracted 179 of signatures.
We know it’s a lot to take in and has become a bit complicated, but it’s why we’re all coming to DC!

• ZERO’s Position:
  We urge Congress to support $110M in funding for the PCRP in the FY 2021 DoD appropriations bill and fight any effort to undermine or eliminate the program in the National Defense Authorization Act.

• ZERO’s Asks
  • Sign the King-Bishop (House) dear colleague letter to the House Appropriations Committee supporting funding for the PCRP program
  • The Crapo-Menendez (Senate) dear colleague letter to the Senate Appropriations Committee will be circulated later in the year
Legislative Priorities

Protecting and Growing

Prostate Cancer Funding at the Centers for Disease Control and Prevention (CDC)
Established in 1998, CDC’s National Comprehensive Cancer Control Program (NCCCP) is a strategic approach to prevent and minimize the impact of cancer in communities.

President’s FY21 budget request eliminated funding within the CDC’s CCC program for prostate cancer activities; Congress has ignored this request since FY17.

Last year (FY2020), Congress added $1M to the CDC budget to support after we requested funding for a new program to do outreach in high-risk populations (African-American men & men with a family history).

**ZERO’s Position:** Provide an additional $2M ($16.2M total) for prostate cancer activities targeting high-risk populations in the Labor-HHS-Education FY21 appropriations bill.

**ZERO’s Ask:** Members include support for this program in their individual communications to the Appropriations Committee.
Prostate Specific Antigen Screening for High Risk Men
USPSTF released finalized its PSA recommendation in May 2018 and improved the screening grade from a “D” to a “C”.

The recommendation mentions the concern about the lack of data on high-risk populations, including African-Americans and family history, due to lack of African American or men with a family history enrollment in clinical trials and suggests that a different recommendation could likely be required for those groups.

The Prostate-Specific Antigen Screening for High-risk Insured Men (PSA Screening for HIM) Act – H.R. 5200 (Reps. Rush (D-IL) and Bucshon (R-IN))

- Waives deductibles, copayments, and coinsurances for prostate cancer screenings for men who have a family history of prostate cancer or who are African-American
- Instructs insurers and government agencies to treat these populations as if they had an “A” grade from USPSTF, which the Affordable Care Act ties to insurance coverage

ZERO’s Position/Ask: Cosponsor H.R. 5200, the PSA Screening for HIM Act
Ensuring our nation’s veterans receive consistent, high quality care

**Prostate Cancer Clinical Pathway at the Veterans Health Administration**
VA Clinical Pathway for Prostate Cancer

• Many large health care systems and several national health programs (Canada & Australia) provide a “clinical pathway” for prostate cancer.

• Clinical Pathway is a plan of care that translates clinical guidelines into a structured and standardized intervention for a specific clinical problem in a specific population of patients. It includes time frames for progression through the pathway.

• Pathways focus on the quality and efficiency of care after decisions have been made about what procedures or services to perform. “Guidelines” are decision support tools for physicians to make evidence-based decisions about treatment options, whereas a pathway may be viewed as a quality assurance tool for a hospital or system.

• Rep. Dunn will soon introduce legislation requiring the VA to develop a clinical pathway for prostate cancer.

• ZERO’s Position/Ask: Cosponsor the Dunn bill when it is released.
Key Takeaways

- Congress should maintain funding at $110M in the FY2021 DoD appropriations bill. Sign the King-Bishop (House) Crapo-Menendez (Senate) dear colleague letter to the House Appropriations Committee supporting funding for the PCRP program.

- Increase funding (from $14.2M to $16.2M) for prostate cancer activities, including outreach to high-risk men, at the CDC in the Labor-HHS-Education FY21 appropriations bill. Ask members to include support for this program in their individual communications to the Appropriations Committee.

- Ask members to cosponsor H.R. 5200 the PSA Screening for HIM Act.

- Ask members to cosponsor the VA prostate cancer clinical pathway bill when introduced.