

## Prostate Cancer Impact Alliance (PCIA) 2022 Report

The Prostate Cancer Impact Alliance (PCIA) aims to identify and address gaps in prostate cancer advocacy, awareness, education, research, and policy. The community strives to optimize progress in several areas.

### The main goals of the PCIA include:

- Research that is intended to improve health outcomes for patients with prostate cancer across the spectrum of the disorder
- Patient, caregiver, and provider intercommunication
- Patient and caregiver knowledge regarding diagnostic and management options
- Shared decision making for men at risk for or diagnosed with prostate cancer
- Equity – of access, outcomes and information – for the highest possible quality of care
- Understanding of challenges affecting risk assessment, diagnosis, management, care, and access to such care – including but not limited to insurance coverage, prior authorization, step therapy, utilization management, non-medical switching, and genetic testing

PCIA is governed by a Steering Committee and an Advisory Board, and works to advance its goals through three issue-based workgroups: (1) Health Equity; (2) Patient/Provider Communication; and (3) Policy and Advocacy.

### 2022 Highlights and Deliverables:

- In January, the PCIA reviewed the Needs Gap Assessment developed by the PCIA: Patient Physician Communications Workgroup.
- In February, the PCIA: Health Equity Workgroup hosted a Black History Month Webinar, *Impact of Diversity in Urology: How Black Urologists Shape Patient Outcomes*. The event consisted of two hour-long panels.
  - In the first panel, Black physicians shared their journeys in their urologic careers, how culturally competent care shapes patient outcomes, and why Black voices are vitally needed in urology. The following metrics reflect social media engagement in the immediate 24 hours following the panel: Twitter - 518 views, 4,574 impressions, 111 Engagements, 14 likes, 10 retweets. Facebook - 232 Views, 713 people reached, 65 Engagements, 17 Reactions/comments/shares
  - In the second panel, Black prostate cancer patients and caregivers shared their personal experiences with the medical system. The following metrics reflect social media engagement in the immediate 24 hours following the panel: Twitter - 301 views, 3,351 impressions, 76 Engagements, 7 likes, 4 retweets Facebook - 136 Views, 374 People Reached, 62 engagements, 12 Reactions/comments/shares
- In March, in partnership with the American Urological Association (AUA), Urology Care Foundation (UCF), KidneyCAN, ZERO: The End of Prostate Cancer, the Bladder Cancer Advocacy Network, and the Kidney Cancer Impact Alliance (KCIA), the PCIA hosted a congressional briefing

to educate and raise awareness about the Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense (DoD). CDMRP programs are a critical source of funding for prostate, kidney and bladder cancer research. The webinar garnered over 70 attendees, including 30+ Congressional staffers. Featured speakers below:

- Dr. Scott Swanson, AUA President Christine Riordan, AUA Director of Research
  - Representatives from patient advocacy organizations KidneyCAN & ZERO: End of Prostate Cancer
  - CDMRP-funded physicians serving as peer reviewers
  - CDMRP consumer reviewers (i.e., patient/survivor advocates with condition/disease of study)
- In April, the PCIA held the first full-alliance meeting of the year. At this meeting, advocates discussed issues and areas of focus that they felt would be important for the PCIA to prioritize on in 2023.
  - In September, the PCIA held the first ever in-person alliance meeting in Washington, D.C., which included work group meetings, a steering committee meeting, a full alliance meeting, and a networking reception. The second day included meetings on Capitol Hill to support the PSA Screening for HIM Act (H.R. 1176). The PSA Screening for HIM Act would ensure that men who are at a higher risk of being diagnosed with prostate cancer, African American men, and men with a family history, are able to access prostate cancer screenings without cost-sharing barriers. There was 20+ organizations in attendance, and a total of 13 congressional meetings.
  - Later in September, the PCIA Health Equity Workgroup hosted the *Impact Series: Men Who Have Sex with Men* webinar. The purpose of this webinar was to address the needs of men who have sex with men who have prostate cancer as they undergo treatment from their urologists and other healthcare providers. This webinar also aimed to make patient advocacy groups and physicians more aware of the challenges and barriers that men who have sex with men face in fighting prostate cancer.
    - The panel included 3 patient advocates and 3 physicians. The below metrics reflect social media engagement in the immediate 24 hours following the panel: Twitter – 273 views, 1,357 impressions, 6 likes, 3 retweets, and 33 link clicks. YouTube - 93 views
  - In November, the PCIA Patient & Physician Communication Workgroup hosted the Impact Series: Emotional Wellness Webinar. The purpose of this webinar was to discuss the importance of emotional health when a patient is diagnosed with prostate cancer and while undergoing treatment. This webinar included perspectives from patients, a physician, a caregiver, and a mental health professional. The below metrics reflect social media engagement in the immediate 24 hours following the panel:
    - Twitter – 37 views, 202 impressions, 1 like, 4 link clicks. YouTube – 37 views

#### **Snapshot of 2023 Goals and Initiatives:**

- Expand Alliance participation, engagement and membership to ensuring well-rounded representation of the prostate cancer patient community
- Use needs gap assessment findings to reprioritize group goals and initiatives

- Continue advocacy for continued/increased federal funding for prostate cancer research
- Continue advancing individual workgroup missions
- Continuing the *Impact Series* webinars exploring new topics including: best practices for serving the trans community during June in recognition of Pride Month; financial assistance programs/related resources available to patients; issues patients face in returning to work post-diagnosis
- Host another educational benign on CDMRP and its important role in the prostate cancer research landscape
- Engage further with the AUA's Research Advocacy Committee and wider AUA community including the AUA Summit and the Urology Telehealth Task Force

**Alliance Participants:**

Active Surveillance Patients International  
 American Cancer Society - Cancer Action Network  
 AnCan Foundation - Answer Cancer Foundation  
 Cancer ABCs  
 Cancer and Careers  
 Cancer Support Community  
 CancerCare  
 FORCE (Facing Our Risk of Cancer Empowerment)  
 Malecare  
 National Alliance of State Prostate Cancer Coalitions  
 Patient Empowerment Network  
 Prostate Cancer Foundation  
 Prostate Cancer International  
 Prostate Cancer Research Institute  
 Prostate Conditions Education Council

Prostate Health Education Network  
 R Frank Jones Urologic Society  
 RetireSafe  
 Sexual Medicine Society of North America  
 Society for Basic Urologic Research  
 Society of Urologic Nurses & Associates  
 Society of Urologic Oncology  
 Society of Women in Urology  
 Stand Up To Cancer  
 Triage Cancer  
 Urology Care Foundation  
 Us TOO Support Groups, ZERO  
 Veterans Prostate Cancer Awareness Inc.  
 ZERO - The End of Prostate Cancer

## Thank You to Our Sponsors!

### Premier Advocacy Supporter



### Advocacy Leader



### Advocacy Friend

