

2021 Prostate Cancer Impact Alliance Report

In effort to expand knowledge, advance research, and improve patient care throughout the prostate cancer community, the American Urological Association, in collaboration with the Urology Care Foundation, created and launched the Prostate Cancer Impact Alliance (PCIA). This collaborative coalition comprises key stakeholders within the prostate cancer community including patients, caregivers, researchers, physicians, and allied health professionals. The coalition framework is designed to remove barriers to patient care and improve access to life-saving treatments.

Through convening like-minded stakeholders and discussing policy, awareness, and quality of life issues impacting patients and caregivers, the PCIA aims to accelerate and optimize progress in the following areas:

- Equity – of access, outcomes and information – for the highest possible quality of care;
- Shared decision-making for people at risk for, or diagnosed with, prostate cancer;
- Patient and caregiver knowledge regarding diagnostic and management options;
- Patient, caregiver, and provider intercommunication;
- 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;
- Research intended to improve health outcomes for patients with prostate cancer across the spectrum of this disorder as well as the quality of life of their families.

Highlights of 2021

- In January 2021
 - The Steering Committee voted to change the name of the alliance from the Friends of Prostate Cancer Care Coalition to the Prostate Cancer Impact Alliance
 - The Steering Committee approved a 2021 strategy document
 - The group began using the online platform Mighty Networks
- In February 2021, 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 2021. The group also decided to develop bylaws and restructure the workgroups.
- In March 2021, the PCIA (in partnership with the Kidney Cancer Impact Alliance) hosted an informational webinar on the Congressionally Directed Medical Research Programs

aimed at congressional staffers who may be unfamiliar with the programs. The webinar featured:

- Congresswoman Rosa DeLauro (D-CT-03), Chair of the House Appropriations Committee
- Dr. Scott Swanson, AUA President
- Dr. Carolyn Best, AUA Director of Research and former Director of the Prostate Cancer Research program within the CDMRP
- Representatives from patient advocacy organizations including KidneyCAN
- Physicians funded by the CDMRP and serving as peer reviewers
- CDMRP consumer reviewers

The webinar garnered over 70 attendees, including 30+ Congressional staffers.

- In April
 - The group finalized its logo and marketing materials, which can be seen in the header of this paper.
 - The group hosted a briefing on the Most Favored Nations model rule, and discussed a possible response
 - The group then developed a sign-on letter on the MFN that was sent to the CMS commissioner
- In May, the group held its second quarterly alliance meeting, where the logo was presented and the group discussed the PCIA launch and efforts for Prostate Cancer Awareness Month in September.
- In June, R. Frank Jones Urologic Society joined the PCIA as a new member.
- In July, the PCIA bylaws were finalized and approved by the Steering Committee.
- In August
 - The AUA's Patient Advocacy Liaison, Jacqueline Zarro, joined the PCIA Steering Committee.
 - The group hosted its third quarterly alliance meeting, where the group discussed individual plans for Prostate Cancer Awareness Month, and PCIA launch. They also heard an update from the workgroups.
 - The group developed a telehealth consensus statement
- In September, the group honored Prostate Cancer Awareness Month by launching publicly. As part of launch, a press release was sent out, a splashpage was developed for the PCIA on the Urology Care Foundation website, and individual groups participated by tweeting about their participation in the alliance. ([Link to press release](#)).
- In November, the PCIA held its final full alliance meeting of the year. The meeting included a year in review, and a discussion of upcoming events and goals.
- In December
 - The group held focus groups with Todd Carrick of the AUA, on needs gaps in the community.
 - The group inaugurated a new Steering Committee.

Deliverables in 2021

- At the beginning 2021, the PCIA sent a letter to the Biden Administration Transition team to introduce the group members and note our willingness to work alongside the new Administration, as well as to emphasize the importance of continued research funding for kidney cancer.
- The PCIA created its new logo and branding
- The PCIA finalized its bylaws and strategy documents
- The PCIA hosted a webinar on the Most Favored Nations interim final rule
- The PCIA launched in September of 2021
- The PCIA developed and sent a letter to state Medicaid directors on the Clinical Treatment Act, explaining its relationship to prostate cancer and encouraging its enforcement.
- The PCIA was invited to attend a briefing on telehealth, which included panelists from PCIA member group Cancer Support Community and AUA members.
- The PCIA hosted and supported sign on letters on Most Favored Nations, Telehealth, and the DIVERSE Trials Act.
- The PCIA brought in a scientific advisor, Dr. Roger Li of the AUA's Research Advocacy Committee, who will attend Steering Committee Meetings in 2022.

2022 Goals and Initiatives

- Expand Alliance participation and find new ways to work with and engage the prostate cancer community
- Use needs gap assessment findings to reprioritize group goals and initiatives
- Continue prostate cancer research funding advocacy
- Continue advancing individual workgroup missions
- Host Black History Month Webinar in February
- Host CDMRP Briefing in March
- Engage further with the AUA's Research Advocacy Committee and wider AUA community including the AUA Summit and the Urology Telehealth Task Force
- Explore other leadership opportunities with topics relevant to the prostate cancer community in 2022, such as webinars on policy initiatives and sign-on letter opportunities, as well as federal advocacy
- Host an in-person meeting



PROSTATE CANCER impact alliance

Alliance Participants

1. Active Surveillance Patients International
2. American Cancer Society, Cancer Action Network
3. American Urological Association, Representatives from:
 - a. Legislative and Political Affairs
 - b. Legislative Affairs Committee
 - c. Office of Research
 - d. Patient Advocacy Liaison to Public Policy Council
 - e. Research Advocacy Committee
 - f. State Advocacy Committee
4. Answer Cancer Foundation d/b/a AnCan
5. Cancer ABCs
6. Cancer and Careers
7. CancerCare
8. Cancer Support Community
9. FORCE - Facing Our Risk of Cancer Empowered
10. Malecare
11. National Alliance of State Prostate Cancer Coalitions
12. Patient Empowerment Network
13. Prostate Cancer Foundation
14. Prostate Cancer International
15. Prostate Cancer Research Institute
16. Prostate Conditions Education Council
17. Prostate Health Education Network
18. R Frank Jones Urologic Society
19. RetireSafe
20. Sexual Medicine Society of North America
21. Society for Basic Urologic Research
22. Society of Urologic Nurses and Associates
23. Society of Urologic Oncology
24. Society of Women In Urology
25. Stand Up To Cancer
26. Triage Cancer
27. University of Michigan, Department of Urology
28. Urology Care Foundation* Foundation for the American Urological Association
29. UsToo International* Merged with ZERO – The End of Prostate Cancer at the end of 2021
30. ZERO –The End of Prostate Cancer



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