

2020 | Guide to Common Bladder Cancer Advocacy Terms



Government, Advocacy and Administrative Terms

Affordable Care Act (ACA or Obamacare): Legislation that provides expanded insurance coverage.

American Urological Association: Founded in 1902, the AUA is a premier urologic association, providing invaluable support to the urologic community. Our mission is to promote the highest standards of urological clinical care through education, research and the formulation of health care policy.

Bacille Calmette-Guérin (BCG) has been the gold standard of care for many patients with non-muscle invasive bladder cancer for decades. As a result of many factors, including increased usage, production and shipping difficulties, regulatory burdens and the shutdown of capacity, there is a critical shortage of BCG available in the United States to treat bladder cancer patients.

Congressionally Directed Medical Research Programs (CDMRP): The CDMRP is a Department of Defense (DOD) program that receives congressional appropriations explicitly for biomedical research in specific, congressionally identified health matters. As such, it is not part of the President's budget request for the DOD. The U.S. Army Medical Research and Development Command (USAMRDC) administers the CDMRP and is responsible for awarding and managing competitive grants.

Defense Health Research Consortium (DHRC): A membership organization for advocacy groups to ensure research funding through the Department of Defense grants.

Financial Toxicity: The idea that the costs of treating cancer can be so severe they impact upon a patient's quality of life, becoming an adverse effect themselves.

Food and Drug Administration (FDA): Oversees all drug and device development in the U.S. Offers many resources and panels for patients and other key stakeholders

HIPAA: HIPAA is the federal Health Insurance Portability and Accountability Act of 1996. The primary goal of the law is to make it easier for people to keep health insurance, protect the confidentiality and security of healthcare information and help the healthcare industry control administrative costs.

One Voice Against Cancer (OVAC): A network of cancer advocacy groups dedicated to increasing appropriations for cancer research through NIH, NCI, DOD, and CDC.

PCORI (Patient Centered Outcomes Research Institute): An independent nonprofit, nongovernmental organization located in Washington, DC, whose mandate is to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions. Authorized by Congress in 2010 as part of a modification to the Social Security Act by clauses in the Patient Protection and Affordable Care Act (Obamacare), PCORI funds comparative clinical effectiveness research, or CER, and work that will improve the methods used to conduct such studies. PCORI supports the BCAN Patient Survey Network.

Rally for Medical Research - The purpose of the Rally is to call on our nation's policymakers to make funding for National Institutes of Health (NIH) a national priority and raise awareness about the importance of continued investment in medical research that leads to MORE PROGRESS, MORE HOPE and MORE LIVES SAVED.

Veteran's Health Council: A forum for health organizations working to improve health care for veterans.