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Commentary

A “Delicate Dance”

Establishing a Process for Assessing and Endorsing Cancer-Related Policy

By John DeMuro



John DeMuro is the director of federal legislative affairs at Moffitt Cancer Center and the chair of AACI's Government Relations Steering Committee.

Commentary Overview

- AACI cancer centers face a dilemma when deciding whether to endorse cancer-related legislation, which may require the use of limited funds from the NIH and NCI.
- Legislative initiatives, including the Cancer Moonshot, have historically played a role in setting scientific policy.
- Ultimately, AACI cancer centers must assess policy measures on a case-by-case basis to determine how they may benefit patients with cancer in their catchment areas.

When it comes to appropriations and legislation that directly impact scientific policy, AACI cancer centers face a dilemma. Although cancer centers may choose to collaborate with elected officials to enact specific priorities, these priorities may be at odds with the overall scientific direction and funding decisions of government agencies including the National Institutes of Health (NIH) and National Cancer Institute (NCI).

From the perspective of these agencies, legislative language that is overly directive may be perceived as minimizing the peer review process in identifying promising opportunities. Furthermore, due to finite financial resources, existing priorities may go under- or unfunded. However, some legislative initiatives have enormous potential to accelerate progress against cancer, reduce cancer mortality, and boost investments in the research conducted at cancer centers. Their value to the cancer center network cannot be understated.

For example, the [PREVENT HPV Cancers Act \(HR 1550\)](#), proposed earlier this year by **Representative Kathy Castor (D-FL)**, would establish a public awareness campaign under the direction of the Centers for Disease Control and Prevention (CDC) to educate Americans on cancers caused by the human papillomavirus (HPV). The legislation also aims to increase HPV vaccination rates, especially among adolescent boys, Black and Hispanic women, and other communities disproportionately impacted by these cancers. The legislation would reduce disparities in early detection by expanding funding for the CDC's National Breast and Cervical Cancer Early Detection Program, ensuring timely access to screening and diagnostic services among low-income, uninsured, and underserved women. Increased NCI funding would be required to meet another goal of the legislation: to expand, intensify, and coordinate research on HPV-associated cancers.

Despite the many positive aspects of the bill, some members of the cancer advocacy community have expressed concerns with language that recommends the use of limited NCI funds to accomplish its goals — potentially pulling resources from other cancer-related priorities and disease groups.

A History of Scientific Policy-Setting

The PREVENT HPV Cancers Act is not the first piece of legislation to direct the use of NCI funds. Within the past decade alone, several major congressional initiatives have played a key role in setting scientific policy.

Established in Bethesda, Maryland in 2011, the [National Center for Advancing Translational Sciences \(NCATS\)](#)—one of the NIH's 27 institutes and centers—aims to transform the translation of scientific discoveries to deliver treatments and cures faster. NCATS accelerates the process of finding new therapies through programs like Discovering New Therapeutic Uses for Existing Molecules. In 2015, scientists supported by the program found that an experimental compound originally developed as a cancer therapy showed promise as a potential treatment for Alzheimer's disease.

In another example, the [Recalcitrant Cancer Research Act \(HR 733\)](#) was signed into law in 2013 with broad bipartisan and bicameral support, as part of the National Defense Authorization Act. The bill calls on the NCI to develop scientific frameworks for pancreatic and lung cancers, and gives the NCI director authority to develop frameworks for other lethal cancers.

Measures like these—as well as the Obama administration's [Cancer Moonshot](#) initiative, launched in 2016, and President Biden's proposed \$6.5 billion [Advanced Research Projects Agency for Health \(ARPA-H\)](#) initiative—would likely receive wide support from cancer centers and cancer organizations today. Yet they are clear examples of scientific policy-setting by elected officials.

Striking a Balance

Many cancer centers and related organizations refrain from endorsing legislation that might impact funding decisions by the NIH and NCI. As an organization representing 102 leading cancer centers in North America, AACI does not take such decisions lightly. At the recommendation of government relations staff and other experts at cancer centers, the AACI Board of Directors reviews relevant legislation with an eye toward the overall benefits to patients with cancer, to the cancer research enterprise, and to AACI member institutions. Ideally, AACI cancer centers and other cancer advocacy organizations will be empowered to evaluate legislative proposals on a case-by-case basis, guided by an honest assessment of these benefits.

In my view, the role of AACI member centers—including my home institution, Moffitt Cancer Center—is to offer the guidance of our scientific and medical experts on the extent to which a given policy measure might advance cancer prevention and cures in our own catchment areas. While we might also legitimately weigh in on questions of prioritization and political feasibility, these concerns are ultimately resolved through the interplay between Congress and federal agencies.

In his former role as majority staff director of the U.S. Senate Labor-HHS-Education Appropriations Subcommittee under **Senator Tom Harkin (D-IA)**, [Edward Long, PhD](#), says the

subcommittee was judicious with mandates, most often opting to “encourage” or “urge” agencies, rather than “direct” them to make specific decisions.

“It’s a delicate dance between the role of science and the role of Congress,” said Dr. Long, who is now vice president of Washington, DC-based government affairs firm, Van Scoyoc Associates. “We have to recognize that there is already—and there will always be—funding targeted by Congress for specific diseases and scientific aims, but you have to strike a balance.”

Our Mission

The Association of American Cancer Institutes (AACI) comprises 102 premier academic and freestanding cancer centers in the United States and Canada. AACI is accelerating progress against cancer by empowering North America’s leading cancer centers in their shared mission to alleviate suffering.

About AACI Commentary

To promote the work of its members, AACI publishes *Commentary*, a monthly editorial series focusing on major issues of common interest to North American cancer centers, authored by cancer center leaders and subject matter experts.

