



NATIONAL HEALTH COUNCIL

NEWS

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NIH Funding, FDA and Medicare Part D Top Policy Priorities for Patient Groups

WASHINGTON, Sept. 26 — Leaders from national patient groups gathered on Capitol Hill today to promote increased funding for the National Institutes of Health (NIH), to ensure that any new prescription drug safety measures do not restrict access to medications, and to make recommendations about improving Medicare Part D.

"Today, under the umbrella of the National Health Council, you will hear the collective voice of some 100 million Americans with chronic conditions and disabilities who are represented by our member patient groups," said Myrl Weinberg, president, National Health Council (NHC). "They are here to provide the patient perspective on health care policy and to explain how Congress can help to improve and prolong their lives."

NIH Funding

Patient groups recommended FY 2007 funding of \$29.95 billion for NIH, a five percent increase (\$1.43 billion) over FY 2006. The groups also urged that any NIH reauthorization be consistent with the findings of the Institute of Medicine report ***Enhancing the Vitality of the NIH: Organizational Change to Meet New Challenges***.

"Investing in NIH innovation translates into saving and improving lives, saving money, spurring our nation's economic growth and keeping America competitive," said John W. Walsh, NHC board chairperson and chief executive officer, Alpha-1 Foundation.

Walsh also presented findings from a new NHC report focusing on how NIH funding yields tangible results. The report, [**Investing in Innovation**](#), was released at the event.

FDA

With respect to the Food and Drug Administration (FDA), the groups said any measures to improve prescription drug safety must be balanced with patients' access to effective medications and not interfere with their rights to make informed decisions

about medications with their physicians.

The patient groups also called for reauthorization of the Prescription Drug Fee User Act and adequate resources for a drug approval process that delivers safe, effective medicines as quickly as possible for people living with chronic conditions.

To enhance innovation in the drug approval process, the groups voiced continued support for FDA's "Critical Path" initiative.

"We in the patient community recognize the need for a balanced approach between safety and access," said Margaret C. Kirk, NHC vice chairperson and chief executive officer, Y-ME National Breast Cancer Organization. "That's why we seek to help Congress understand that the burden of living with chronic diseases or disabilities often far exceeds the potential side effects of treatments. Patients and their family caregivers demand the right to make informed decisions about their medications in consultation with their physicians."

Findings from [Benefits of Innovation](#), a report looking at access, safety, benefit and risk from the patient perspective and released at the briefing, helped to inform the NHC's policy recommendations.

Medicare Part D

Patient groups urged Congress to guarantee access to medications under Medicare Part D by providing gap coverage that includes both branded and generic options, by offering lowest-tiering payments for drugs that do not have a generic equivalent and by eliminating co-payments for dual-eligibles.

The groups recommended the creation of a standardized, user-friendly appeals and exceptions process as well as the development of a consistent protocol for notifying beneficiaries of changes in, or the elimination of, their plans.

The groups also asked Congress to continue its policy protecting the six classes of medicines including anticonvulsants, antidepressants, anticancer drugs, antipsychotics, immunosuppressants and HIV/AIDS drugs.

Finally, the patient groups called for an end to the exclusion of life-saving medications such as benzodiazepines and barbiturates often prescribed for epilepsy and mental health conditions such as Alzheimer's, depression and bipolar disorder and for pain management of diseases like cancer.

"While this program is a tremendous benefit for millions of Americans who previously did not have access to medications, we need to ensure that enrollees, especially those with chronic conditions, do not face life-threatening barriers," said Eric R. Hargis, NHC immediate past chairperson and president and CEO, Epilepsy Foundation. "For some vulnerable beneficiaries, especially for those eligible for both Medicare and Medicaid, cost-sharing mechanisms are hindering access to medications and resulting in catastrophic outcomes — meaning unnecessary emergency room visits and extended hospital stays."

[Access to Innovation](#), an NHC-commissioned environmental scan to evaluate Medicare Part D implementation from the patient perspective, also was released at the briefing.

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The National Health Council is a private, nonprofit umbrella organization of 115 national health-related organizations working to bring quality health care to all people. Its core membership includes some 50 of the nation's leading voluntary health agencies representing about 100 million people with chronic diseases and/or disabilities. Other Council members include professional and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical and biotechnology companies. The Council serves as a place for diverse health-related groups to build consensus with a focus on patients and their needs.

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