



22 National Patient Organizations Voice Concerns to Department of Health and Human Services Removing Key Opportunity for Public Voice

WASHINGTON, D.C. (March 6, 2025) – On Monday, the Department of Health and Human Services (HHS) published a document in the Federal Register announcing rescission to a long-standing policy that required HHS to conduct public notice and comment procedures on a wide range of agency action. Patient groups representing millions of people with serious health conditions issue the following statement:

“Our organizations express deep concerns with this sudden policy change published in the Federal Register on Monday. The notice and comment process provides an invaluable platform for patients to share real world experiences, concerns, and implications of the proposed rules, generating valuable feedback to agencies and other policymakers. This process allows the public to actively participate in the development of health care regulations, which can and has led to policies that better address patient needs and improve access to quality care.

“Removing the notice and comment process significantly limits transparency into agency action that has a direct impact on patients accessing essential health services. Our organizations are concerned that some policies could be finalized or rescinded without notice or public scrutiny, and that this process could create confusion among health care stakeholders, including state and local governments, and the health care providers our patients rely on.

“On behalf of the millions of patients we represent, we urge the Department of Health and Human Services to swiftly reconsider and reverse this policy change.”

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AiArthritis
American Cancer Society Cancer Action Network
American Kidney Fund
American Lung Association
Asthma and Allergy Foundation of America
Crohn's & Colitis Foundation
Cystic Fibrosis Foundation
Epilepsy Foundation of America
Family Voices
Hemophilia Federation of America
Lutheran Services in America

Muscular Dystrophy Association
National Bleeding Disorders Foundation
National Health Council
National Kidney Foundation
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Patient Advocate Foundation
Pulmonary Hypertension Association
Susan G. Komen
The AIDS Institute
The Leukemia & Lymphoma Society

