



**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 Our organizations are concerned that some policies could be finalized or rescinded without notice or public scrutiny, and that this process could create confusion among health care stakeholders, including state and local governments, and the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 | Muscular Dystrophy Association |
| American Cancer Society Cancer Action Network | National Bleeding Disorders Foundation |
| American Kidney Fund | National Health Council |
| American Lung Association | National Kidney Foundation |
| Asthma and Allergy Foundation of America | National Multiple Sclerosis Society |
| Crohn's & Colitis Foundation | National Organization for Rare Disorders |
| Cystic Fibrosis Foundation | National Patient Advocate Foundation |
| Epilepsy Foundation of America | Pulmonary Hypertension Association |
| Family Voices | Susan G. Komen |
| Hemophilia Federation of America | The AIDS Institute |
| Lutheran Services in America | The Leukemia & Lymphoma Society |

