



News From . . .

U.S. Rep. Christopher Cox

California

<http://cox.house.gov>

Contact: Kate Whitman
(202) 225-5611

Cox Act Will Aid 25 Million Americans With Rare Diseases

Ensures Continuing Medicare Coverage For Orphan Drugs

WASHINGTON (Friday, July 11, 2003) - Representative Christopher Cox (R-CA), Chairman of the House Policy Committee and Chairman of the Homeland Security Committee, today introduced the Medicare Patient Access to Drugs for Rare Diseases Act of 2003. The Act is co-sponsored by Representatives Norwood (R-GA), Issa (R-CA), Engel (D-NY), Boucher (D-VA), Berman (D-CA), and Pomeroy (R-CA).

The Medicare Patient Access to Drugs for Rare Diseases Act of 2003 will ensure that Medicare beneficiaries have continued access to critical orphan drugs, in addition to providing pharmaceutical manufacturers with renewed incentives to continue developing these life-saving medical treatments.

More than 25 million Americans suffer from one of 6,000 rare diseases as catalogued by the National Institutes of Health. Included among these 6,000 diseases are Huntington's disease, ALS (Lou Gehrig's disease), primary pulmonary hypertension, porphyria, muscular dystrophy, cystic fibrosis, tuberous sclerosis, and hemophilia. Twenty years ago, Congress passed the Orphan Drug Act of 1983 to stimulate the development of new treatments for persons afflicted with these rare diseases. Since then, more than 240 new "orphan drugs" have been approved by the Food and Drug Administration.

When Congress adopted the Medicare Hospital Outpatient Prospective Payment System in 1999, it placed orphan drugs in a category that provided sufficient reimbursement for these treatments to assure continuing access for rare disease patients. Unfortunately, in 2003 the Center for Medicare and Medicaid Services implemented new rules which only covered four orphan drugs. As a result, Medicare reimbursement for all other orphan drugs will be cut by as much as 35 percent, which will impose severe

financial burdens on hospitals who want to continue to provide that latest treatments to people who suffer from these rare diseases.

“Our bill clarifies Congressional intent under the 1999 law to ensure that all orphan drugs will be covered,” said Chairman Cox. “Without this bill, beneficiaries who suffer from rare diseases may be denied treatment because healthcare providers refuse to administer orphan drugs. Congress can not allow this to happen.”

For more information, please go to <http://cox.house.gov>

###