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108TH CONGRESS
1ST SESSION

H. CON. RES. 147

IN THE SENATE OF THE UNITED STATES

MAY 20, 2003

Received and referred to the Committee on the Judiciary

CONCURRENT RESOLUTION

Commemorating the 20th anniversary of the Orphan Drug Act and the National Organization for Rare Disorders.

Whereas Congress passed, and President Ronald Reagan signed into law on January 4, 1983, the Orphan Drug Act;

Whereas there are many diseases and conditions, such as Huntington's disease, myoclonus, ALS (Lou Gehrig's disease), Tourette syndrome, and muscular dystrophy, that affect such small numbers of individuals—populations under 200,000—residing in the United States that the diseases and conditions are considered rare;

Whereas there are 6,000 known rare diseases and conditions, affecting approximately 25,000,000 Americans;

Whereas these rare diseases and conditions are sometimes referred to as ‘‘orphan’’ diseases and conditions, and drugs (including biological products) to treat them are sometimes referred to as ‘‘orphan drugs’’;

Whereas, prior to 1983, because so few individuals were affected by any one orphan disease or condition, a pharmaceutical company that developed an orphan drug may have reasonably expected the drug to generate relatively small sales in comparison to the cost of developing the drug and, therefore, to incur a financial loss;

Whereas the object of the Orphan Drug Act was to stimulate the development of orphan drugs;

Whereas the Orphan Drug Act is one of the most successful Federal laws enacted in the last 20 years;

Whereas, prior to 1983, less than 40 therapies existed to treat orphan diseases and conditions as compared today to the more than 238 drugs, foods, and devices that now exist to treat an estimated 11,000,000 patients in the United States;

Whereas 85 percent of orphan drugs are being used to treat serious or life-threatening diseases, 31 percent treat rare forms of cancer, and approximately 50 percent are approved for pediatric uses;

Whereas the National Organization for Rare Disorders, established in 1983, is a federation of voluntary health organizations dedicated to helping people with orphan diseases and conditions and assisting the organizations that serve them; and

Whereas the National Organization for Rare Disorders is committed to the identification, treatment, and cure of orphan diseases and conditions through programs of education, advocacy, research, and service: Now, therefore, be it

Resolved by the House of Representatives (the Senate concurring), That the Congress celebrates the 20th anniversary of the Orphan Drug Act and the National Organization for Rare Disorders, and recognizes the great contributions the Orphan Drug Act has made to the rare disease community.

Passed the House of Representatives May 19, 2003.

Attest: JEFF TRANDAHL,

Clerk.