

103<sup>D</sup> CONGRESS  
1<sup>ST</sup> SESSION

# H. R. 2652

To amend the Public Health Service Act to provide for the establishment through the National Institutes of Health of a data system and an information clearinghouse with respect to rare diseases.

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## IN THE HOUSE OF REPRESENTATIVES

JULY 15, 1993

Mr. ROEMER introduced the following bill; which was referred to the Committee on Energy and Commerce

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## **A BILL**

To amend the Public Health Service Act to provide for the establishment through the National Institutes of Health of a data system and an information clearinghouse with respect to rare diseases.

1        *Be it enacted by the Senate and House of Representa-*  
2        *tives of the United States of America in Congress assembled,*

3        **SECTION 1. SHORT TITLE.**

4        This Act may be cited as the “Jonathan Tomal Rare  
5        Diseases Public Information Act”.

1 **SEC. 2. ESTABLISHMENT OF DATA SYSTEM AND INFORMA-**  
2 **TION CLEARINGHOUSE WITH RESPECT TO**  
3 **RARE DISEASES.**

4 Part A of title IV of the Public Health Service Act  
5 (42 U.S.C. 281 et seq.), as amended by section 207 of  
6 Public Law 103–43, is amended by adding at the end the  
7 following section:

8 “DATA SYSTEM AND INFORMATION CLEARINGHOUSE  
9 REGARDING RARE DISEASES

10 “SEC. 404E. (a) DATA SYSTEM.—The Director of  
11 NIH, acting through the appropriate national research in-  
12 stitutes, shall establish the National Rare Diseases Data  
13 System for the collection, storage, analysis, retrieval, and  
14 dissemination of data derived from patient populations  
15 with rare diseases, disorders, or other health conditions,  
16 including where possible, data involving general popu-  
17 lations for the purpose of detection of individuals with a  
18 risk of developing such diseases, disorders, or conditions.

19 “(b) INFORMATION CLEARINGHOUSE.—The Director  
20 of NIH, acting through the appropriate national research  
21 institutes, shall establish the National Rare Diseases In-  
22 formation Clearinghouse to facilitate and enhance,  
23 through the effective dissemination of information, knowl-  
24 edge and understanding of rare diseases, disorders, and  
25 other health conditions by health professionals, patients,  
26 and the public.

1       “(c) AUTHORIZATION OF APPROPRIATIONS.—For the  
2 purpose of carrying out this section, there are authorized  
3 to be appropriated \$3,000,000 for fiscal year 1994, and  
4 such sums as may be necessary for each of the fiscal years  
5 1995 and 1996.”.

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