

IN THE HOUSE OF REPRESENTATIVES

HOUSE CONCURRENT RESOLUTION NO. 9

BY HEALTH AND WELFARE COMMITTEE

A CONCURRENT RESOLUTION

1 STATING FINDINGS OF THE LEGISLATURE AND SUPPORTING EFFORTS TO ALLEVIATE THE  
2 EFFECTS OF RARE DISEASES ON IDAHOANS.  
3

4 Be It Resolved by the Legislature of the State of Idaho:

5 WHEREAS, nearly 7,000 diseases and conditions are considered rare, and  
6 though each affects fewer than 200,000 Americans, rare diseases as a group  
7 affect almost 30 million Americans; and

8 WHEREAS, many rare diseases are serious and debilitating conditions  
9 that have a significant impact on the lives of those affected; and

10 WHEREAS, Idaho is ranked last in the nation for the number of pediatric  
11 physicians per capita; and

12 WHEREAS, there are only 250 pediatric physicians in Idaho, and 110 are  
13 located in Boise; and

14 WHEREAS, there are only eight pediatric neurologists in Idaho, six of  
15 whom practice in Boise; and

16 WHEREAS, pediatric physicians and neurologists have an average waiting  
17 list of eight to nine weeks; and

18 WHEREAS, once a diagnosis of "rare disease" is made, many Idaho patients  
19 are referred to neurological clinics in surrounding states for evaluation  
20 and treatment; and

21 WHEREAS, travel for evaluation and treatment is a financial and emo-  
22 tional hardship for patients, families and caregivers; and

23 WHEREAS, individuals and families affected by rare diseases often ex-  
24 perience problems such as a sense of isolation, difficulty in obtaining an  
25 accurate and timely diagnosis, limited treatment options and difficulty ac-  
26 cessing or being reimbursed for treatment; and

27 WHEREAS, thousands of Idaho residents are among those affected by rare  
28 diseases, as nearly one in ten Americans has a rare disease.

29 NOW, THEREFORE, BE IT RESOLVED by the members of the First Regular Ses-  
30 sion of the Sixty-fourth Idaho Legislature, the House of Representatives and  
31 the Senate concurring therein, that the Legislature supports efforts to al-  
32 leviate the effects of rare diseases on Idahoans, and especially on Idaho  
33 children, including efforts to educate pediatric physicians about rare dis-  
34 eases, to coordinate communication among pediatric physicians, specialists  
35 and patients, to increase patient access to pediatric neurologists, and to  
36 recruit more pediatric neurologists to practice in this state.